



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Literature Review: Family burden and coping responses in OCD: a narrative review; 2) Service Improvement Project: Transition experiences of patients and parents to an adult cystic fibrosis service; 3) Main Research Project: Social anxiety and self-perceptions of social performance in adolescents and young adults with high functioning autism spectrum disorders.

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Doctorate in Clinical Psychology

Main Research Portfolio

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Doctorate in Clinical Psychology

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May 2014

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Abstracts

Main Project

This study aimed to 1) investigate if adolescents and young adults with autism spectrum disorder (ASD) who are high in social anxiety underestimate their social performance when compared with those low in social anxiety, and 2) investigate the association between social motivation and social anxiety. Participants (n=20) aged 14-21 years completed measures of social anxiety, loneliness and social satisfaction before taking part in a video-recorded group discussion. Self and observer ratings of social performance were analysed. Results revealed that participants high in social anxiety rated themselves significantly poorer than did observers. The interaction between social anxiety group and rater was non-significant. Loneliness significantly correlated with social anxiety. This study highlights how cognitive factors may be involved in social anxiety for young people with ASD and discusses implications for psychological intervention.

Service Improvement Project

Objective: Chronic illness, such as Cystic Fibrosis, can make adolescence and young adulthood challenging. During this time, young people must move on from using paediatric to adult healthcare services. This transition is a current research focus, acknowledged to require careful preparation and planning and be considered within a developmental context. This study aimed to explore the experiences of some young people with Cystic Fibrosis and their parents during this transition in order to inform a transition pathway. *Method:* Five young people and three parents who were either approaching or had experienced transition were interviewed about their experiences. Transcribed interviews were analysed using thematic analysis. *Results:* Four key themes emerged: moving on from the familiarity and security of children's services; changes in the nature of relationships with healthcare professionals; transition as a condensed process in the context of adolescence; and changing roles in healthcare. *Conclusions:* Results highlighted the strong attachment to paediatric team and the anxiety

about change for both patients and parents. Themes are discussed along with service recommendations which aim to reduce this anxiety for patients by supporting the establishment of new relationships and increase familiarity and confidence with the new setting and processes.

Literature Review

Family members often become significantly involved in obsessive compulsive disorder, changing their lives to accommodate the symptoms. Relatives can experience distress, and feel a great deal of burden relating to the OCD. Families are recognised as a key factor in treatment effectiveness and therefore understanding their burden and how they cope is essential. The aim of this review was to synthesize studies concerned with family burden and coping in OCD to build on the understanding of family experiences and help inform treatment. A search was conducted of Pub Med, Web of Science and APA Psych NET using terms OCD, burden, coping, family, relatives etc. Thirteen articles were included in the review. Burden was found to be a far-reaching and complex construct associated with increased severity of OCD, dysfunction, family accommodation and depressive symptoms. Families have been reported to struggle to know how to cope. Avoidant coping has been associated with decreased hope, negative affect and accommodation whereas active reframing and social support appear to have the opposite associations. Results are discussed along with implications for treatment and further areas of research.

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Journal targeted for publication: *Clinical Child and Family Psychology Review*
(see appendix A)

This journal was selected due to the relevance of its content and the inclusion of in-depth reviews that pertain to areas of psychology as applied to families. Furthermore, a previous review in this area was published in this journal.

Abstract

Family members often become significantly involved in obsessive compulsive disorder, changing their lives to accommodate the symptoms. Relatives can experience distress, and feel a great deal of burden relating to the OCD. Families are recognised as a key factor in treatment effectiveness and therefore understanding their burden and how they cope is essential. The aim of this review was to synthesize studies concerned with family burden and coping in OCD to build on the understanding of family experiences and help inform treatment. A search was conducted of Pub Med, Web of Science and APA Psych NET using terms OCD, burden, coping, family, relatives etc. Thirteen articles were included in the review. Burden was found to be a far-reaching and complex construct associated with increased severity of OCD, dysfunction, family accommodation and depressive symptoms. Families have been reported to struggle to know how to cope. Avoidant coping has been associated with decreased hope, negative affect and accommodation whereas active reframing and social support appear to have the opposite associations. Results are discussed along with implications for treatment and further areas of research.

Introduction

Family Involvement in OCD and treatment

Obsessive compulsive disorder (OCD) is thought to affect between 1 and 4% of adults and children and typically emerges during childhood or adolescence (Geller et al., 1998). OCD exists in a social and interpersonal context and it is widely acknowledged that family members are often inextricably involved in symptoms (Waters, 2000). Families may respond to OCD symptoms on a continuum from accommodating symptoms of OCD to responding in a hostile manner, perhaps reflecting the dilemma that families face (Waters, 2000). OCD can have a major impact on the emotional wellbeing and functioning of the entire family system (Cooper, 1996). This may be particularly pertinent in children who are more dependent on the system around them, however, literature has suggested that in adults too, OCD brings with it an increased dependence on

family members who feel a significant degree of stress and burden (Laidlaw et al., 1999).

There are clear recommendations to involve family members in treatment of OCD (NICE, 2005) particularly in childhood OCD. A key reason for this is the high rate of family accommodation and the negative influence that this can have on treatment outcome (Garcia, 2010). Family accommodation has become a prominent area of research interest and refers to how families participate in the disorder by, for example, participating in rituals, providing reassurance, changing family routines around OCD symptoms, facilitating avoidance strategies and assuming daily responsibilities for the sufferer. Such responses are carried out with the intentions of reducing ritual engagement and distress for both patient and family member. However, accommodation is known to maintain OCD symptoms and is associated with negative affect and distress in the family members (e.g. Amir et al., 2000).

Several studies (e.g. Amir et al., 2000; Calvocoressi et al., 1999; Caporino et al., 2012; Peris et al., 2008; Storch et al., 2007) have been carried out to investigate correlates and predictors of family accommodation in order to understand what drives these behaviours and target this area in treatment. A recent review of these studies found that accommodation is consistently and strongly related to symptom severity and appears to be increased in cases of cleaning and contamination related OCD (Lebowitz et al., 2012). Treatments that have included family elements (e.g. Freeman et al., 2008; Storch et al., 2007) have shown some improvement in outcome, however the review by Lebowitz concluded that there is currently insufficient evidence to show that family treatments are more effective than individual treatment (Lebowitz, 2012). A couples-based OCD treatment approach has been developed by Abramowitz et al. (2012) which puts great emphasis on the importance of exploring the couple's relationship with OCD. Components of the approach include understanding the couple's history with OCD and how they have structured their environment to accommodate OCD, teaching partner-assisted exposure and enhancing communication through "emotional expressiveness training". A pilot study of this approach has received promising results showing improvements in relationship

functioning at post-test and improvements in OCD which were maintained at one year follow-up (Abramowitz et al., 2013).

Given the high level of involvement of family members, the distress and disruption that can be experienced and the influence of the family on the course of OCD, including the family in treatment seems essential. It is probable that increasing understanding of family experiences, coping responses and burdens will help to add value to treatment approaches.

Models and measurement of burden in family members

An emerging area of literature is concerned with the burden that OCD can place on family members. Lebowitz (2012) highlights the complex relationship between burden and accommodation behaviours; families may accommodate symptoms to reduce burden however increasing involvement may increase the burden experienced. The concept of burden is broad, encapsulating the financial, physical, and emotional effects of caring for someone with a chronic and disabling condition. Both *family-* and *caregiver-* burden have both been referred to, the latter focussing on the consequences for the main caregiver as opposed to the wider effect on the whole family system.

The multifaceted nature of burden means that attempts at measuring the construct unidimensionally have been criticised for "masking dimension specific patterns" and are perceived by some to not accurately or fully assess the construct (George and Gwyther, 1986). Burden is often measured by separating objective and subjective burden. Objective burden refers to the tasks of caring, while subjective burden is the perception of the impact of the objective burden (Montgomery et al., 1985) or how much one *minds* carrying out the tasks (Jones, 1996). The Zarit Burden Interview (Zarit et al., 1980) is one of the most consistently used measures of subjective burden which produced a global core. The Caregiver Burden Inventory (Novak and Guest, 1989) is another widely used measure which separates burden into the subscales of physical burden, social burden, emotional burden, time dependency and developmental burden. Family burden measurements, such as the Family Burden Interview Schedule (Pai and Kapur, 1981), contain scales relating to disruption of family life, e.g.

family leisure activities, family interactions, as well as financial burden and the mental and physical health of others. Understanding burden associated with being a family member of someone with OCD has important implications for supporting and engaging them in treatment.

Models of coping

Appraisals and coping responses have been conceptualised as mediating the relationship between stressor and outcomes such as burden in caregivers (Morano, 2003). OCD can be seen as being a chronic stressor for families with far-reaching effects (Glynn and Liberman, 1990). Families must cope with the disruption, distress and uncertainty that OCD brings about. As previously discussed, accommodating symptoms appears to be a common way of coping with OCD.

A review by Kramer and Vitaliano (1994) found that much of the caregiving literature is based on Lazarus and Folkman's model which conceptualised stress as resulting from an imbalance between one's appraisals of demands and resources. The process of coping has been defined as the cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman, 1984). Distinctions were made between problem- versus emotion-focused coping, and active- versus avoidant-coping. Generally, it is thought that one employs problem-focused, active strategies if a person perceives they have control over the threat.

Several questionnaires to assess coping styles have been developed based on the distinctions made by Lazarus and Folkman. The Coping Responses Inventory (Moos, 1997) contains 48 items that measure cognitive and behavioural coping according to approach (e.g. positive reappraisal, social support and problem solving) and avoidance (e.g. cognitive avoidance, resigned acceptance, emotional discharge). One of the most widely used measures is the COPE questionnaire (Carver, Scheier & Weintraub, 1989). This 52 item questionnaire comprises 13 scales that distinguish between problem and emotion focused coping. Following criticism of there being too many factors, a

factor analytic study of 587 National Health Service employees identified a three factor structure of emotion-focused coping, rational or active coping and avoidance (Lyne and Roger, 2000). Another frequently used measure is Ways of Coping Questionnaire (Folkman and Lazarus, 1980), which contains 8 subscales of confrontative coping, seeking social support, planful problem solving, self-control, distancing, positive appraisal, accepting responsibility, escape avoidance.

An area of literature relevant to appraisals and coping looks at the concept of hope. Hope has been defined in different ways, for example Dufault and Martocchio (1985) offer the definition of "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving future good...". This definition captures how hope allows one to hold conflicting expectations as described by Folkman (2010). Hope is considered to be a key psychological resource when dealing with caring (Folkman, 2010). Folkman describes an interplay between coping and hope in that each can facilitate each other. The concept of hope has been studied in the chronic illness literature such as oncology (e.g. Lohne et al., 2012) and has been shown to hold some relationship with family caregiver strain experienced. Although it has received surprisingly little attention within the field of mental health, it would be hypothesised to be an important factor for family members of individuals with anxiety disorders such as OCD.

Rationale and Aims of Review

It is clear that families can become heavily involved in OCD and engaging them in treatment is best practice. In order to successfully involve families in treatment there is a need to understand their experience, recognise their own needs and understand their coping responses. Although this area of research has been relatively neglected, a research base is emerging investigating the experiences of family members, the burden of OCD and coping. This review aimed to synthesize this literature base, identify gaps for further research and help inform family-based approaches. This review did not include articles primarily focused on family accommodation as this has been reviewed elsewhere (Lebowitz et al., 2012). The review included articles focusing on different family members,

families of both adult and child probands and included quantitative, qualitative and mixed methods approaches.

Method

The inclusion criteria for this review were for studies (a) focused on the impact of- or coping responses to having a family member with OCD, thus addressing the aim of the review (b) included participants who had a family member with a diagnosis of OCD in accordance with OCD or DSM criteria (c) published in the English language (d) published between the year 2000 and 2013 inclusive.

Search Strategy

Pub Med, APA Psych NET and Web of Science were used to search for relevant articles. A search limit was used for English language and published between January 2000 and December 2013. This timeframe was decided due to the review of family involvement published in 2000 by Waters and colleagues. Multiple search terms were used to find relevant articles. These were "obsessive compulsive disorder OR OCD" AND "family"/"parents"/"relatives"/"spouses" etc. AND "impact"/"burden"/"coping"/"hope". These searches yielded 502 articles. Duplicates were removed and additional references were retrieved from the reference lists of articles found. Titles and abstracts were screened for relevance to the review and full articles obtained for those that met the inclusion criteria. This resulted in a total of 13 articles being included in the review.

Results

Burden on family members

Eight papers were found to primarily focus on family or caregiver burden in OCD and are displayed in Table 1. Three of these studies used the Zarit Burden Interview, four used the Family Burden Interview Scale and one used the Burden Assessment Scale.

Comparisons with other psychological difficulties

Three of these papers compared burden for family members of OCD patients with those of schizophrenia patients, with two finding comparable levels (Gururaj et al., 2008; Jayakumar et al., 2002). Thomas et al. (2004) found that families of those with schizophrenia reported greater burden, although families of OCD patients still reported considerable burden. Thomas et al. (2004) found that dysfunction of OCD patients was significantly and positively correlated with four areas of family burden: financial burden, disruption of family routine, disruption of family leisure activities and disruption of family interactions.

Table 1: Summary of family burden studies

| Study (year) | Adult/child patients | Criteria for family members/caregivers contributing | n | Comparison group (n) | Instrument used for measurement of burden | Key findings |
|---------------------|-----------------------------|--|----------|---|--|---|
| Cicek et al. (2013) | Adult | First degree relatives | 45 | Relatives of healthy hospital employees (45). | Zarit Burden Interview | Positive correlations found between ZBI, age of onset, duration of illness, duration of treatment, frequency of hospitalisation, YBOCS total score. All quality of life subscales negatively correlated with burden. Independent predictor of ZBI: co-morbid mood disorders in OCD patients, poorer insight of patients, duration. |
| Grover (2011) | Ages 16-62 | Primary caregiver, >18 years old, living with patient for at least one year. | 50 | - | Family Burden Interview Schedule | 56% high objective burden, subjective burden moderate in 56% and severe in 44%. Severity of illness correlated with burden. Greater objective burden, disruption of family leisure activities and interactions led to significantly poorer quality of life for caregivers. Higher subjective burden was associated with poorer general and psychological quality of life. |

Table 1: Summary of family burden studies cont.

| | | | | | | |
|-------------------------------|-------|--|----|---|-------------------------------|--|
| Jayakumar et al. (2002) | Adult | Key relatives who had cared for patient for at least 2 years (14 parents, 13 spouses, 3 others). | 30 | Relatives of patients with Schizophrenia. | Burden Assessment Scale | Relatives of OCD group had significantly higher scores for spouse related areas and caregiver strategy. Groups were comparable on other domains of burden. Total burden was higher in spouses as compared with parents and other relatives. |
| Ramos-Cerquiera et al. (2008) | Adult | Primary caregiver as indicated by the patient based on level of intimacy and involvement with problem. | 50 | - | Zarit Burden Interview | Accommodation, emotional burden and psychological comorbidity were all associated with each other and with severity of patients' OCD. No significant associations between total burden and age of onset, clinical course of OCD, living with patient, and some demographic variables. Presence of depressive symptoms among patients was only independent predictor to remain significant following regression analysis. |
| Siu et al. (2012) | Adult | Caregivers living with patient for at least one year (43 spouses, 25 parents, 5 children, 4 siblings). | 77 | - | Family Burden Interview Scale | 99% experienced objective burden, mothers had greatest subjective burden. Global Assessment of Functioning explained variance of objective (41.5%) and subjective burden (49.8%). |

Table 1: Summary of family burden studies cont.

| | | | | | | |
|----------------------|-------------|--|----|---|-------------------------------|--|
| Thomas et al. (2004) | Ages 15-50. | First degree relative living with the patient for at least the previous three years. | 30 | First degree relatives of patients with Schizophrenia (n=35). | Family Burden Interview Scale | Most variables measured e.g. disruption of family-routine, disruption of family leisure and interactions and financial were higher in the Schizophrenia group. Positive correlations were found between patient dysfunction and all areas of family burden except physical and mental health in the OCD group. |
| Torres et al. (2012) | Adult | Family caregivers indicated by patient as most closely involved in his/her symptoms. | 47 | - | Zarit Burden Interview | ZBI factor analysis study to identify dimensions of burden. Six factors explained 74.2% of ZBI total variance: interference of personal life, perception of dependence, feelings of irritation or intolerance, feelings of guilt, feelings of insecurity, and feelings of embarrassment. All factors associated with OCD severity and accommodation. Some factors associated with specific family and caregiver variables. |
| Vikas et al. (2011) | Adult | Healthy relative >18 years old, staying with them regularly for at least one year. | 32 | Relatives of depressed patients (n=30) | Family Burden Interview Scale | Burden was experienced in several areas. Relatives of the OCD patients were more burdened and had to accommodate to greater degree than caregivers of depressed despite patients themselves reporting better quality of life and being less disabled than depressed patients. |

Jayakumar et al. (2002) used the Burden Assessment Scale to compare the burden experienced in relatives of OCD patients and Schizophrenia patients. As mentioned, in the majority of domains the burden experienced was comparable between these groups. However, the OCD group were elevated in spouse related areas, showing poor support, inadequate satisfaction of emotional and sexual needs and deteriorated marital satisfaction. The OCD group also scored more highly on the caregivers' strategy scale suggesting less support from friends and feeling the need for temporary separation. Total burden was higher in spouses than other relatives, however this may be due to an over representation in the sample. All in all, this study demonstrated the high level of stress and strain among relatives and the tremendous burden that OCD can have on marital relationships.

A comparison with depressed patients found that despite the patients with OCD reporting better quality of life and being less disabled than depressed subjects, family members were more burdened and accommodated symptoms to a greater extent (Vikas et al., 2011). This supports the notion that OCD is a particularly burdensome condition for relatives.

Relationship between burden and clinical variables

The degree of total burden has been found to be associated with severity of OCD symptoms (Cicek et al., 2013; Ramos-Cerqueira et al., 2008; Siu et al., 2012). Cicek and colleagues also found positive correlations between burden (using ZBI) and age of onset, duration of illness, duration of treatment and frequency of hospitalisation, along with negative correlations with all aspects of quality of life. It is understandable why duration of illness and severity would be associated with greater burden. Cicek and colleagues suggested that a later age of onset may affect caregivers perceptions of the disorder, perhaps viewing it more as an uncontrollable disease rather than due to personal characteristics and therefore finding it harder to accept. However, Ramos-Cerqueira et al. (2008) did not find that a significant difference in age of onset in those scoring high in burden as compared with low.

Predictors of burden

Ramos-Cerqueira et al. (2008) found burden to be associated with appraisal of distress for caring (as measured by a single item on the family accommodation scale), accommodation, self evaluation of health, severity of depression and severity of OCD symptoms. Siu et al. (2012) also found functional level of the patient, as measured by the Global Assessment of Functioning, to explain 41.5% of the variance in burden.

Regression analyses have revealed independent predictors of burden to be comorbid mood disorders/depressive symptoms in patients (Cicek et al., 2013; Ramos-Cerqueira et al., 2008), poorer insight of patients and duration of OCD (Cicek et al., 2013). These findings suggest that depressive symptoms that co-occur with OCD, possibly as a result of OCD, may have a specific impact on caregiver burden. Patient insight and mood are likely to affect motivation for change in the person affected and possibly place greater responsibility on the caregiver. In the aforementioned two studies, a unidimensional approach to measuring burden was taken. Using a multifactorial approach may have led to a better understanding of the burden experienced and the relationship with the other variables.

Factor Analysis of Burden

Torres et al. (2012) conducted a factor analysis of the ZBI with caregivers of OCD patients aiming to describe the most relevant factors and the associations between factors and multiple family, caregiver and clinical variables. Six factors were identified to explain 74.2% of ZBI total variance: interference of personal life; perception of dependence; feelings of irritation or intolerance; feelings of guilt; feelings of insecurity; and feelings of embarrassment. All these factors were positively associated with accommodation and symptom severity. Contrary to the findings of Cicek et al. (2013), none of the factors were significantly associated with clinical variables such as age of onset, course and previous treatment. Caregiver psychological morbidity was related with factors of interference with personal life, perception of dependence, feelings of insecurity and feelings of embarrassment. Some sociodemographic variables related with specific factors; occupation status as not working was related to interference with

personal life and perception of dependence. A higher educational level was related with greater feelings of embarrassment. However, age, marital status, religious practice were not related with any factors.

Findings from studies of parent and caregiver experiences

A high degree of burden has been indicated in narratives of parents of children with OCD (Futh et al., 2012). Parents described a far reaching impact, with OCD affecting individuals, marital relationships and the whole family system. Parents described being overwhelmed and emotionally exhausted which was linked to being involved in lengthy rituals. Some spoke of being unable to work as their child could not attend school and they feared distress if they were left alone. The consequence of this was loss of social connectedness and loneliness.

In the qualitative study by Stengler-Wenzke et al. (2004), feeling responsible for the relative with OCD was experienced as burdensome. Having a vague diagnosis, insufficient knowledge and the stigma attached to psychiatric treatment was reported to place burden on relatives.

Storch et al. (2009) investigated parental experience of having a child with OCD using a tool developed for use in paediatric chronic illness; the Parent Experience of Chronic Illness (PECI; Bonner et al., 2006). Responses were compared to the sample of parents of children with brain tumour used in the development of the tool. Analysis showed that long term uncertainty experienced by the parents was comparable between the samples suggesting a significant degree of concern among parents regarding their children's ability to function in the future. The three distress domains (guilt/worry, unresolved sorrow and anger and long term uncertainty) were positively related to parental distress and caregiver strain, symptom severity, impairment and accommodation. Emotional resources domain was negatively related with parental distress and caregiver strain.

Coping

As Futh et al. (2012) highlight, relatives need to cope with not only the impact of OCD on their loved one, but the personal and familial consequences.

Table 2: Summary of coping studies

| Study (year) | Adult/child patients | Criteria for family members/caregivers contributing | n | Comparison group (n) | Instrument used for measurement of coping | Key findings |
|------------------------|-----------------------------|--|----------|--|--|---|
| Derisley et al. (2005) | Children aged 11-18 years | Parents | 28 | Other anxiety disorders (n=28) and no known health problems (n=62) | Coping Responses Inventory | OCD and other anxiety disorders groups of parents used more avoidant coping. OCD group were particularly elevated in behavioural avoidance. |
| Futh et al. (2012) | Children aged 9-18. | Parents | 71 | - | Ways of Coping Questionnaire | Mothers reported using all coping strategies more often than fathers especially escape avoidance, taking responsibility and social support. Escape avoidance coping positively related with negative affect and accommodation. Narratives conveyed a distressing struggle between engaging in- and resisting OCD. |
| Geffken et al. (2006) | Mixed, aged 5-76 | Spouses and primary caregivers. | 67 | - | COPE Inventory, Hunter Opinions and | Hope negatively related with depressive symptoms, symptom severity, denial disengagement coping. Hope was positively related with positive reframing and social support |

Table 2: Summary of coping studies cont.

| | | | | | | |
|-------------------------------|-------|--------------------------------|----|---|------------------------------|---|
| | | | | | Personal Expectations Scale. | coping. Active reframing, social support and religiosity negatively related to depression in caregivers/spouses. Coping mediated the relationship between hope and depressive symptoms. |
| Stengler-Wenzke et al. (2004) | Adult | Spouses, parents and children. | 22 | - | Narrative interviews | Relatives described a variety of burdens. Coping strategies are also described including assisting and opposing OCD symptoms. |

Despite this, the coping strategies used by relatives has received little research attention. Four articles were found to be relevant to understanding how family members cope, summaries of which are presented in Table 2. These studies all used different ways of measuring coping, with one being qualitative and one using a mixed methods approach.

Coping strategies employed by family members

A cross sectional study measured the use of coping strategies by parents of adolescents with OCD compared with parents of adolescents with other anxiety disorders and a non-clinical group (Derisley et al., 2005). Using the Coping Responses Inventory (Moos, 1997) the two clinical groups reported using more coping strategies overall than the non-clinical group. Parents of anxious children and those with OCD both showed elevated use of cognitive and behavioural avoidance compared with the non-clinical group. Parents of adolescents with OCD used significantly more behavioural avoidance strategies than the non-clinical group. The Coping Responses Inventory asks individuals to consider a recent a stressful event and rate their use of 48 coping responses. Therefore, it is possible that the stressors experienced were notably different between groups and may have prompted different ways of coping. Stressors experienced by parents of clinical groups may be chronic and their coping responses may have changed over time. The cross sectional nature of this study means that no inferences can be made about the maintaining role of avoidant coping.

A mixed methods study of parents of children with OCD (Futh et al., 2012) used the Ways of Coping Questionnaire, with comparisons made between mother and fathers. All strategies were endorsed to a greater extent by mothers than fathers, however in general the strategies were used infrequently and two of the eight scales (confrontive coping and self-controlling) showed low internal reliability. Mothers used social support, accepting responsibility and escape-avoidance significantly more often than fathers.

Associations between coping strategies and negative affect

Futh et al. (2012) also looked at the associations between coping processes, accommodation and negative affect. In mothers, escape-avoidance was significantly positively correlated with negative affect (stress, anxiety and

depression) as was taking responsibility but to a slightly lesser extent. In fathers distancing was consistently related to negative affect. The nature of the relationship between these types of coping and negative affect is not elaborated. It could be hypothesised that by avoiding and distancing, relationships and social connectedness are being compromised, as reflected in the narratives of parents who reported avoiding situations such as asking their child how they were. Taking responsibility is likely to put greater pressure on parents leading to stress. Similarly, Geffken et al. (2005) found that depression was positively related with denial disengagement and negatively associated with active reframing, religiosity and social support. The use of escape-avoidance coping was positively correlated with accommodation in both mothers and fathers (Futh et al., 2012).

Findings from qualitative studies

The narratives reported in Futh et al. (2012) reflected a struggle for parents to know how to cope with OCD. Parents made efforts to resist and not be drawn into the symptoms but also reported fear of aggressive outbursts if they did not assist. They attempted to decrease suffering but experienced guilt when they did intervene.

An earlier study (Stengler-Wenzke, 2004) also used a qualitative approach to explore coping strategies used by 22 family members, including parents, spouses and offspring. Similarly to the dilemma reported in Futh and colleagues, family members reported a lack of confidence in coping strategies and a concern about the “correctness” of what they were doing with relatives alternating between subordinating to and opposing patients' obsessions. Responses were classified by the relatives in terms of their therapeutic value and also according to the effect on their relationship with the person with OCD. These were often contradictory.

Stengler-Wenzke et al. (2004) noted a difference between coping strategies endorsed by spouses and by parents. Spouses were reported to be more resource orientated and focused on strengths. Parents were more focused on burdens related to the OCD. A small sample limits conclusions being made from

this discrepancy, however this finding may promote some hypotheses for further research.

Hope

One paper was found to measure the construct of hope in family members (Geffken et al., 2005). This study looked at hope and its relationship with coping strategies and depression. Hope was found to be negatively related with depressive symptoms and OCD severity. Hope was positively related to active reframing and social support and negatively related to denial disengagement. A mediation analysis found that denial/disengagement strategies mediated the relationship between hope and depressive symptoms suggesting that low hopefulness leads to denial/disengagement which in turn leads to depression. High hopefulness, on the contrary, may make one less likely to use in denial/disengagement coping and protect from resulting depressive symptoms. Hope is also reflected in the narratives reported by Futh et al. (2012) to differing degrees, some reporting that maintaining hope that their child would recover as an important coping strategy. For others, appraisals of OCD as being uncontrollable, incomprehensible, unpredictable and likening their experience as being in the grip of addiction reflected their hopelessness for the possibility of change. Some parents expressed they could not see an end and they had lost their child forever. Hope was also reported in the qualitative study by Stengler-Wenzke et al. (2004). A diagnosis and understanding of OCD helped instil hope in relatives as they had a new frame of reference which helped interpret the behaviour and experiences.

Discussion

It is clear that OCD has a strong interpersonal quality and families can become highly involved in the symptoms and course of the disorder. This review has synthesized 13 studies concerned with family burden and coping to better understand family experiences and inform treatment.

The studies included in this review highlight the high level of burden experienced by family members of people with OCD, which some have found to be comparable with schizophrenia. Burden is far reaching and for family members of individuals with OCD involves a complex mix of emotions including insecurity, guilt, embarrassment and irritation (Torres et al., 2012). Studies have indicated that the more severe and enduring the OCD and the higher the dysfunction, the higher the reported burden. Greater burden has also been found to be associated with the degree of accommodation family members engage in. A consistent relationship was reported between symptom severity and accommodation in a recent review (Lebowitz, 2012). The vicious circle that can form between symptom severity and accommodation appears to affect all dimensions of burden experienced by family (Torres et al., 2012). The way the burden experienced may further fuel this cycle warrants investigation.

It appears that patient comorbid mood disorders and lack of insight may predict to some extent caregiver burden and one can speculate about the mechanism explaining this relationship. It may be that insight reflects motivation for change, placing less responsibility on the family member and increasing hope. Despite findings regarding the role of mood disorders, one study has reported families of OCD patients being more burdened than those of depressed patients despite better quality of life and functioning in the OCD patients themselves. It is likely that depressed symptoms, when in the context of OCD, have a significant impact of the burden that families feel.

It has also been suggested in the literature that OCD places a particular burden on marital relationships, as compared with other psychological disorders (Jayakumar et al., 2002), highlighting the importance of addressing interpersonal aspects of OCD in assessment and treatment. Such findings strengthen the rationale for the use of couples-based approaches as described by Abramowitz et al. (2012) which places emphasis on OCD and the interpersonal relationship. Burden is a complex, multidimensional construct and tools used in its measurement often consist of several distinct factors. The complexity and breadth of the construct has been highlighted in the diverse domains reported in the ZBI factor analysis conducted by Torres et al. (2012). Authors highlight the differences between the domains identified in this population of family and

caregivers as compared with caregivers of dementia patients, with whom the tool was developed. A greater number and diversity of factors was identified suggesting measuring burden in a more specific way for this population may lead to a better understanding of the outcomes for family members of having a relative with OCD.

Lazarus and Folkman's widely applied stress and coping model sees coping responses as mediating outcomes, such as burden and depression. In coping with the stress of having a family member with OCD, avoidance has been highlighted in several studies as being a significant coping strategy used. Avoidant ways of coping such as denial disengagement, distancing and escape avoidance, have been linked with negative affect (Futh et al., 2012; Gefken et al., 2005). Avoidance is likely to impact on relationships, pleasurable activities and normal family life and therefore have an impact on the psychological wellbeing of family members. Avoidance may be a result of the struggle to know how to respond, as captured in family members' narratives (Futh et al., 2012; Stengler-Wenzke et al., 2004). Social support and active reframing have been shown to be negatively related with negative affect in family members, highlighting the importance of supporting these in treatment.

All the studies that assessed coping did so cross-sectionally. It appears that coping with a family member with OCD is complex giving rise to multiple emotions, such as guilt and anxiety, and creating a conflict between which responses appear helpful to maintain a relationship and which are therapeutically valuable (Stengler-Wenzke et al., 2004). Therefore, coping is likely to change over time. It may be that questionnaire measures do not fully capture coping responses, as Futh et al. (2012) reported. It is also possible that coping differs according to the relationship with the family member, as Stengler-Wenzke et al. (2004) tentatively identified.

In line with Folkman's description of the association between hope and coping (Folkman, 2010), the limited research evidence regarding hope in family members of people with OCD (Geffken et al., 2005) has shown increased hope being associated with a decreased use of denial disengagement coping

strategies which in turn impacted the level of depression in family members. It seems that in the face of having a family member with OCD, maintaining hope can be difficult, especially with increased symptom severity, and is linked with active reframing and social support. Hope is a construct that warrants further research, particularly regarding how clinicians can promote hope in families and the impact of hope on treatment outcome.

This review has encompassed literature regarding coping responses and burden. An important aspect of the model that appears to be missing therefore is the appraisals and meanings that may give rise to certain ways of coping. Lazarus and Folkman's model of stress and coping emphasises the importance of primary and secondary appraisals. The meaning and attributions that family members assign to the OCD and the specific perceived threats that OCD brings are likely to be very important in understanding family experiences. A number of studies included in this review touch upon appraisals. For example, appraisals of OCD being uncontrollable and unpredictable (e.g. Futh et al., 2012), appraisals of long term uncertainty and helplessness (Storch et al., 2009) may lead to avoidance coping and decreased hope. It is important to foster confidence in family members regarding their coping resources and develop a shared understanding of OCD that offers hope and perceptions of controllability. Investigation of families' specific OCD-related appraisals is a worthwhile area of future study to help tie together the findings in this review.

There is a current focus on improving treatment of OCD by including family members to ensure they do not accommodate symptoms and hinder treatment outcome. Reviewing the literature on the burden and coping responses of family members has highlighted the complexity of their experience which needs to be addressed with each family. The construct of burden has been largely studied with relatives or caregivers of adult OCD patients as opposed to child. There is a gap in understanding the particular burdens that parents with a child with OCD feel. Furthermore, utilising longitudinal study designs and establishing clinical evidence will lead to a better understanding of change over time and the relationships between appraisals, coping responses and outcomes such as burden.

References

- Abramowitz, J. S., Baucom, D. H., Boeding, S., Wheaton, M. G., Pukay-Martin, N. D., Fabricant, L. E., Paprocki, C. & Fischer, M. S. (2013). Treating Obsessive-Compulsive Disorder in Intimate Relationships: A Pilot Study of Couple-Based Cognitive-Behavior Therapy. *Behav Ther*, 44(3), 395-407.
- Abramowitz, J. S., Baucom, D. H., Wheaton, M. G., Boeding, S., Fabricant, L. E., Paprocki, C., & Fischer, M. S. (2013). Enhancing Exposure and Response Prevention for OCD: A Couple-Based Approach. *Behavior Modification*, 37(2), 189-210. doi: 10.1177/0145445512444596
- Amir, N., Freshman, M., & Foa, E. B. (2000). Family distress and involvement in relatives of obsessive-compulsive disorder patients. *J Anxiety Disord*, 14(3), 209-217.
- Calvocoressi, L., Mazure, C. M., Kasl, S. V., Skolnick, J., Fisk, D., Vegso, S. J., Van Noppen, B.L. & Price, L. H. (1999). Family accommodation of obsessive-compulsive symptoms - Instrument development and assessment of family behavior. *Journal of Nervous and Mental Disease*, 187(10), 636-642. doi: 10.1097/00005053-199910000-00008
- Caporino, N. E., Morgan, J., Beckstead, J., Phares, V., Murphy, T. K., & Storch, E. A. (2012). A structural equation analysis of family accommodation in pediatric obsessive-compulsive disorder. *Journal of Abnormal Child Psychology*, 40(1), 133-143. doi: 10.1007/s10802-011-9549-8
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). ASSESSING COPING STRATEGIES - A THEORETICALLY BASED APPROACH. *Journal of Personality and Social Psychology*, 56(2), 267-283. doi: 10.1037//0022-3514.56.2.267
- Cicek, E., Cicek, I. E., Kayhan, F., Uguz, F., & Kaya, N. (2013). Quality of life, family burden and associated factors in relatives with obsessive-

compulsive disorder. *Gen Hosp Psychiatry*, 35(3), 253-258. doi:
10.1016/j.genhosppsy.2013.01.004

Cooper, M. (1996). Obsessive-compulsive disorder: Effects on family members. *American Journal of Orthopsychiatry*, 66(2), 296-304. doi:
10.1037/h0080180

Derisley, J., Libby, S., Clark, S., & Reynolds, S. (2005). Mental health, coping and family-functioning in parents of young people with obsessive-compulsive disorder and with anxiety disorders. *British Journal of Clinical Psychology*, 44(3), 439-444. doi: 10.1348/014466505X29152

Dufault, K., & Martocchio, B. C. (1985). HOPE - ITS SPHERES AND DIMENSIONS. *Nursing Clinics of North America*, 20(2), 379-391.

Folkman, S. (2010). Stress, coping, and hope. *Psycho-Oncology*, 19(9), 901-908. doi: 10.1002/pon.1836

Folkman, S., & Lazarus, R. S. (1980). AN ANALYSIS OF COPING IN A MIDDLE-AGED COMMUNITY SAMPLE. *Journal of Health and Social Behavior*, 21(3), 219-239. doi: 10.2307/2136617

Freeman, J. B., Garcia, A. M., Coyne, L., Ale, C., Przeworski, A., Himle, M., . . . Leonard, H. L. (2008). Early childhood OCD: Preliminary findings from a family-based cognitive-behavioral approach. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(5), 593-602. doi:
10.1097/CHI.0b013e31816765f9

Futh, A., Simonds, L. M., & Micali, N. (2012). Obsessive-compulsive disorder in children and adolescents: Parental understanding, accommodation, coping and distress. *Journal of Anxiety Disorders*, 26(5), 624-632. doi:
10.1016/j.janxdis.2012.02.012

Garcia, A. M., Sapyta, J. J., Moore, P. S., Freeman, J. B., Franklin, M. E., March,

- J. S., & Foa, E. B. (2010). Predictors and Moderators of Treatment Outcome in the Pediatric Obsessive Compulsive Treatment Study (POTS I). *J Am Acad Child Adolesc Psychiatry*, 49(10), 1024-1033. doi: 10.1016/j.jaac.2010.06.013
- Geffken, G. R., Storch, E. A., Duke, D. C., Monaco, L., Lewin, A. B., & Goodman, W. K. (2006). Hope and coping in family members of patients with obsessive-compulsive disorder. *Journal of Anxiety Disorders*, 20(5), 614-629. doi: 10.1016/j.janxdis.2005.07.001
- Geller, D. A., Biederman, J., Jones, J., Shapiro, S., Schwartz, S., & Park, K. S. (1998). Obsessive-compulsive disorder in children and adolescents: A review. *Harvard Review of Psychiatry*, 5(5), 260-273. doi: 10.3109/10673229809000309
- George, L. K., & Gwyther, L. P. (1986). CAREGIVER WELL-BEING - A MULTIDIMENSIONAL EXAMINATION OF FAMILY CAREGIVERS OF DEMENTED ADULTS. *Gerontologist*, 26(3), 253-259.
- Glynn, S., & Liberman, R. P. (1990). *FUNCTIONING OF RELATIVES AND PATIENTS FACING SEVERE MENTAL-ILLNESS*.
- Grover, S., & Dutt, A. (2011). Perceived burden and quality of life of caregivers in obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences*, 65(5), 416-422. doi: 10.1111/j.1440-1819.2011.02240.x
- Gururaj, G. P., Math, S. B., Reddy, J. Y., & Chandrashekar, C. R. (2008). Family burden, quality of life and disability in obsessive compulsive disorder: an Indian perspective. *Journal of Postgraduate Medicine*, 54(2), 91-97.
- Jayakumar, C., Jagadheesan, K., & Verma, A. N. (2002). Caregiver's burden : a comparison between obsessive compulsive disorder and schizophrenia. *Indian Journal of Psychiatry*, 44(4), 337-342.

- Jones, S. L. (1996). The association between objective and subjective caregiver burden. *Archives of Psychiatric Nursing*, 10(2), 77-84. doi: 10.1016/s0883-9417(96)80070-7
- Kalra, H., Nischal, A., Trivedi, J. K., Dalal, P. K., & Sinha, P. K. (2009). Extent and determinants of burden of care in Indian families: A comparison between obsessive-compulsive disorder and schizophrenia. *International Journal of Social Psychiatry*, 55(1), 28-38. doi: 10.1177/0020764008091438
- Laidlaw, T. M., Falloon, I. R. H., Barnfather, D., & Coverdale, J. H. (1999). The stress of caring for people with obsessive compulsive disorders. *Community Mental Health Journal*, 35(5), 443-450. doi: 10.1023/a:1018734528606
- Lazarus, R. S. F., S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Lebowitz, E. R., Panza, K. E., Su, J., & Bloch, M. H. (2012). Family accommodation in obsessive-compulsive disorder. *Expert Review of Neurotherapeutics*, 12(2), 229-238. doi: 10.1586/ern.11.200
- Lohne, V., Miaskowski, C., & Rustoen, T. (2012). The Relationship Between Hope and Caregiver Strain in Family Caregivers of Patients With Advanced Cancer. *Cancer Nursing*, 35(2), 99-105. doi: 10.1097/NCC.0b013e31821e9a02
- Lyne, K., & Roger, D. (2000). A psychometric re-assessment of the COPE questionnaire. *Personality and Individual Differences*, 29(2), 321-335. doi: 10.1016/s0191-8869(99)00196-8
- Montgomery, R. J. V., Gonyea, J. G., & Hooyman, N. R. (1985). CAREGIVING AND THE EXPERIENCE OF SUBJECTIVE AND OBJECTIVE BURDEN. *Family Relations*, 34(1), 19-26. doi: 10.2307/583753

- Moos, R. H. (1997). A measure of approach and avoidance coping skills. In C. P. Zalaquett, Wood, R.J. (Ed.), *Evaluating Stress: A Book of Resources* (pp. 51-65): Scarecrow Press: Lanham.
- Novak, M., & Guest, C. (1989). APPLICATION OF A MULTIDIMENSIONAL CAREGIVER BURDEN INVENTORY. *Gerontologist*, 29(6), 798-803.
- Pai, S., & Kapur, R. L. (1981). THE BURDEN ON THE FAMILY OF A PSYCHIATRIC-PATIENT - DEVELOPMENT OF AN INTERVIEW SCHEDULE. *British Journal of Psychiatry*, 138(APR), 332-335. doi: 10.1192/bjp.138.4.332
- Peris, T. S., Bergman, R. L., Langley, A., Chang, S., McCracken, J. T., & Piacentini, J. (2008). Correlates of accommodation of pediatric obsessive-compulsive disorder: parent, child, and family characteristics. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(10), 1173-1181. doi: 10.1097/CHI.0b013e3181825a91
- Ramos-Cerqueira, A. T., Torres, A. R., Torresan, R. C., Negreiros, A. P., & Vitorino, C. N. (2008). Emotional burden in caregivers of patients with obsessive-compulsive disorder. *Depression and Anxiety*, 25(12), 1020-1027. doi: 10.1002/da.20431
- Siu, B. W. M., Lam, C. L., & Chan, W. C. (2012). Pattern and determinants of burden in Chinese families of adults with obsessive-compulsive disorder. *Journal of Anxiety Disorders*, 26(1), 252-257. doi: 10.1016/j.janxdis.2011.11.008
- Stengler-Wenzke, K., Trosbach, J., Dietrich, S., & Angermeyer, M. C. (2004). Coping strategies used by the relatives of people with obsessive-compulsive disorder. *Journal of Advanced Nursing*, 48(1), 35-42. doi: 10.1111/j.1365-2648.2004.03166.x
- Storch, E. A., Geffken, G. R., Merlo, L. J., Jacob, M. L., Murphy, T. K., Goodman,

W. K., Larson, M.J., Fernandez, M. & Grabill, K. (2007). Family accommodation in pediatric obsessive-compulsive disorder. *Journal of Clinical Child and Adolescent Psychology*, 36(2), 207-216. doi: 10.1080/15374410701277929

Thomas, J. K., Suresh Kumar, P. N., Verma, A. N., Sinha, V. K., & Andrade, C. (2004). Psychosocial dysfunction and family burden in schizophrenia and obsessive compulsive disorder. *Indian Journal of Psychiatry*, 46(3), 238-243.

Torres, A. R., Hoff, N. T., Padovani, C. R., & Ramos-Cerqueira, A. T. (2012). Dimensional analysis of burden in family caregivers of patients with obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences*, 66(5), 432-441. doi: 10.1111/j.1440-1819.2012.02365.x

Vikas, A., Avasthi, A., & Sharan, P. (2011). Psychosocial impact of obsessive-compulsive disorder on patients and their caregivers: a comparative study with depressive disorder. *International Journal of Social Psychiatry*, 57(1), 45-56. doi: 10.1177/0020764010347333

Waters, T. L., & Barrett, P. M. (2000). The role of the family in childhood obsessive-compulsive disorder. *Clinical Child and Family Psychology Review*, 3(3), 173-184.

Zarit, S. H., Reever, K. E., & Bachpeterson, J. (1980). RELATIVES OF THE IMPAIRED ELDERLY - CORRELATES OF FEELINGS OF BURDEN. *Gerontologist*, 20(6), 649-655.

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Service Improvement Project: Transition experiences of patients and parents to an adult cystic fibrosis service.

Word count: 4,575 (excluding abstract, tables and references).

Internal supervisor: Dr. Joanna Adams

Field supervisor: Dr. Samantha Phillips

Journal targeted for publication: *Health Psychology* (see appendix B)

This journal was selected due to its high impact factor and the inclusion of qualitative research. This journal emphasises the impact of psychosocial factors on health, highly relevant to this study.

Abstract

Objective: Chronic illness, such as Cystic Fibrosis, can make adolescence and young adulthood challenging. During this time, young people must move on from using paediatric to adult healthcare services. This transition is a current research focus, acknowledged to require careful preparation and planning and be considered within a developmental context. This study aimed to explore the experiences of some young people with Cystic Fibrosis and their parents during this transition in order to inform a transition pathway. *Method:* Five young people and three parents who were either approaching or had experienced transition were interviewed about their experiences. Transcribed interviews were analysed using thematic analysis. *Results:* Four key themes emerged: moving on from the familiarity and security of children's services; changes in the nature of relationships with healthcare professionals; transition as a condensed process in the context of adolescence; and changing roles in healthcare. *Conclusions:* Results highlighted the strong attachment to paediatric team and the anxiety about change for both patients and parents. Themes are discussed along with service recommendations which aim to reduce this anxiety for patients by supporting the establishment of new relationships and increase familiarity and confidence with the new setting and processes.

Key words: Transition, Cystic Fibrosis, patient, healthcare, paediatric

Introduction

The life expectancy of individuals living with Cystic Fibrosis (CF) has dramatically improved recently (Dodge et al., 2007). Therefore, supporting patients through adolescence and planning for adulthood with CF is a relatively new aspect of healthcare. The complex lifetime medical management of CF places great restrictions on young people (Foster et al., 2001) and in most paediatric cases, parents are heavily involved in the treatment regime. Parents can invest years in developing the optimal care for their child. CF can also disrupt peer relationships (Badlan, 2006); exacerbations of symptoms often lead to prolonged periods of

hospitalization and school absenteeism. Therefore, CF alters many aspects of growing up.

Adolescence and transition

Adolescence is described as a time of much growth and uncertainty (Conway, 1998), when we discover who we are as individuals and as members of the wider society (Erikson, 1963). Young people can struggle moving into adulthood with chronic illness, taking on more responsibilities and considering their future (Dovey-Pearce et al., 2005). Young people may experience a conflict between the adolescent task of gradually separating from their parents and their healthcare needs (Stam et al., 2006) which can also present challenges for parents.

Transition from paediatric to adult healthcare services can be a risky time for young people. Some research has shown that engagement with healthcare services lessens and health deteriorates around the time of transferring (McDonagh, 2006). The importance of improving this process has been highlighted in a number of government documents (Department of Health, 2006, 2008). Young people need adequate support and preparation, not always recognised by services, so they don't face the 'cliff edge' that some families have reported (McDonagh, 2006).

Parents play an important role in supporting transition. A third of healthcare professionals reported that parental and family factors influence successful transition, for example, parents' reluctance to withdraw from the young person's care (Shaw et al., 2004). Due to parents' heavy involvement in healthcare in conditions such as CF, getting the balance of input right during transition to foster autonomy but also care for the young person can be difficult (Allen et al., 2011).

To improve transition between child and adult services the Department of Health has issued good practice guidelines (Department of Health, 2008). This guidance includes developing an individualised health transition plan based on the views of the young person. This plan includes aspects such as identifying the young

person's aspirations and goals, helping the young person understand and access adult healthcare, exploring opportunities for independent living and identifying areas of unmet needs. Further recommendations in the literature include starting transition early to instil self-confidence, sharing information between services, involving nurses to oversee transition and providing transition clinics with members of both teams (Reiss et al., 2005).

CF and transition

Transition literature and guidance has also been published specific to CF. The Royal College of Physicians of Edinburgh (RCPE) Transition Steering Group (2009) identified a number of patient and parent concerns regarding transition in CF services from the literature available. Patient concerns included developing trust in unfamiliar carers, accepting an unfamiliar care environment, fear of change, the need to take on responsibilities and the need to deal with change without the support of peers (healthy or those with CF). Parent concerns included the need to develop trust in a new team, loss of contact with the existing healthcare team and the loss of control.

A qualitative study by Brumfield and Lansbury (2004) highlighted the close relationship with the paediatric doctor and unfamiliarity with the new doctor being perceived as a huge step for patients. Important elements of a transition programme identified by the participants included having a tour of the adult clinic, having a familiar face at the adult clinic and recognition of the ongoing importance of their parents in supporting self management.

The RCPE (2009) outline best practice guidelines which were established from reaching a consensus view from CF centres around the UK, rather than being drawn from research evidence. Guiding principles of transition include the patient and parent being comfortable and confident in meeting the adult team, that anxieties are addressed, that transfer does not come as a surprise and is perceived as an accomplishment by patient and family. The roles of both the paediatric team and adult team in preparing the patient and family are outlined.

Service context

Each year approximately four young people make the move from the paediatric CF service in a children's hospital in UK to the adult service in the adjoining hospital. The current protocol is that the young people are invited to attend two “transition clinics” in the year preceding the transfer in which staff from the new adult team are introduced. No formal preparation programme or planning is in place. However, staff report that they informally discuss the move, the changes to be expected and any worries that arise. There are mixed opinions within the teams about whether an improved pathway is needed to better prepare the young people for moving on. Some clinicians have concerns that a number of young people find transition difficult and struggle adapting to adult services. As a result some stop attending clinic appointments and their health deteriorates. Due to these concerns a CF transition steering group made up of professionals from both the adult and paediatric teams started convening quarterly to develop the ways that transition is managed.

Aims and rationale

The value of consulting young people and their parents about their experiences of transition was highlighted by members of the transition steering group to help inform any changes in how transition is managed. This qualitative study aimed to:

- 1) Explore the experiences of patients and their parents during the transition from paediatric to adult CF services.
- 2) Identify the challenges and helpful factors in their preparation for the adult service.
- 3) Identify any further help and support the young people and parents would have found helpful.
- 4) Present findings to both teams with service recommendations to improve the management of transition.

Method

Design

A cross-sectional qualitative approach using semi structured interviews was selected due to the exploratory nature of this research.

Ethical approval

Ethical approval was given for the study by the Research and Development department of the NHS trust (Appendix C) and the University Of Bath Psychology Research Ethics Committee (Appendix D). As this study constituted a service evaluation, full National Research Ethics Service approval was not deemed necessary.

Participants

Young people aged 16-20 who had transferred to the adult CF service within the last 18 months or who were due to transfer in the next 18 months were included. Parents of these young people were also contacted to be interviewed. No specific exclusion criterion was applied as it was hoped that any young person who met these criteria could be included.

Procedure

A member of the CF team approached all the individuals who met the inclusion criteria and gave them verbal information about the study. If consent was given, the families were contacted by the researcher and sent written participant information sheets. They were then contacted a second time to arrange the interview. Written consent was obtained from all participants prior to the interviews. Participants chose whether the interviews took place at home or following a clinic appointment at the hospital in a private room. They also chose whether they were interviewed alongside their relative or alone. Interviews were audio recorded and transcribed.

Interviews

Semi-structured interviews took place with each participant which lasted between 40 and 75 minutes. Several stem questions (Table 1) that formed the topic guide

were developed with the transition steering group, however interviews were free to follow relevant lines of enquiry that arose for the individual.

Table 1: Stem questions used in semi-structured interviews

| |
|---|
| <ul style="list-style-type: none"> • How were you/ are you being prepared for using adult services? • What have been the main changes and challenges you have encountered in the transition to adult services? • What has helped you in the transition process? • What further help would have been helpful? • What other comments or feedback do you have about you experience transitioning to adult services? |
|---|

Analysis

Thematic analysis was used to identify themes in the data. This method of analysis is not bound to a specific theoretical framework and therefore offered flexibility to consider both personal meanings and the wider social context. Thematic analysis has been criticised for lack of methodological rigor, therefore this study followed the phases outlined by Braun and Clarke (2008). This process consisted of familiarisation with data, generation of initial codes, searching for themes, reviewing themes and defining and naming of themes. The lead researcher carried out this process. To promote reliability of the analysis, an independent rater also read and coded transcripts and noted key emerging themes. These were compared with the researcher and discussed. This credibility check occurred at two other time points during the analysis. A data trail was kept so that the researcher could identify how themes had developed over time.

Results

Participants

From a pool of 12 patients and families who met the inclusion criteria, 8 families gave consent to be contacted. From these, five young people took part and three parents. These were all female patients and mothers. One of these young people (D) was pre-transfer (aged 16) and the remaining participants (A, B, C and E)

had transferred in the last 18 months (aged 18-20). In the three families where the parent also took part, two opted to be interviewed with the young person and one opted to be interviewed separately.

Themes

Four key themes emerged from the data, presented in Table 2, containing between 2 and 5 subthemes.

1. Moving on from the familiarity and security of the children's service
2. Changes in the nature of relationships with health care professionals
3. Transition as a condensed process in the context of adolescence
4. Changing roles in healthcare.

Table 2: Themes and key quotations from the data

| Theme | | Quotations |
|---|--|---|
| Moving on from the familiarity and security of the children's service | a) Anxiety and reluctance to move on | <p><i>'For [yp] she was in a bit of denial because she really didn't want to go' (Parent A).'</i></p> <p><i>'... it was mentioned on and off ... as she got up to secondary school... we'd just joke and laugh it off thinking we're not going [laughs]'(Parent C).</i></p> <p><i>' Over in children's they got people who are 20 odd with cancer... Their consultants decide whether they keep them on... My illness is just as bad....there isn't a cure and you're ready to ship us off?!' (E)</i></p> <p><i>'I know someone who's come over and since they come over they're got worse so that's what's putting a lot of us off from coming over'. (E)</i></p> <p><i>'There's always a worry that things are going to be missed but it's all gone well'. (Parent B)</i></p> |
| | b) Stepping out from a trusted family into the unknown | <p><i>'It's not knowing who those people are [adult team], because you put all your trust in those people. And you think they're not going to be as good but they are'. (C)</i></p> <p><i>'People that I didn't know were going to take over her care. And we knew these people at the children's for so many years. [My daughter] was diagnosed at 22 months, she was no more than a baby when they took up her care....I trusted them absolutely and for that to come to an end!' (Parent C).</i></p> <p><i>'It was difficult to talk to the adult consultants because I didn't know them... they didn't know us. I didn't feel I could go in as a mum and offload, whereas if I had been in the paediatric service... we've known them for 15/16 years (Parent A).</i></p> <p><i>It's people I don't know, new people... I don't feel prepared for the new people and how it's going to be'. (D)</i></p> |
| | c) Not fitting in on the adult ward | <p><i>'On the ward there were so many old people, they were screaming during the night and trying to escape, turning over with their big bare bottoms sticking out, it's a totally different set up.' (Parent A).</i></p> <p><i>'In children's you had the CF nurse who came to see you and say "are you alright today?" so I had a bit of company. Over here you don't so you're on your own.' (E)</i></p> <p><i>'When they're on the ward they do feel isolated. More on adults than when they're on children's because</i></p> |

Table 2: Themes and key quotations from the data cont.

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| | | <p><i>when they're on children's they have a play therapist or teaching, they've got some structure... Sometimes she got really lonely.'</i> (Parent B)</p> <p><i>'They could say, 'why don't you spend a night over here [on the adult ward] just so you can get used to it'.</i> (E)</p> |
| | d) Parents withdrawing comfort on the adult ward | <p><i>'When [my daughter] was in the children's hospital I spent as much time as I could there with her. When I've gone into the adult service I can't stay overnight, I think that's part of the transition process for the parents... she's still my little girl. It's hard walking out knowing that she's an adult in an adult hospital'</i> (Parent A)</p> <p><i>'As parents we need to be encouraged not to spend so much time in the paediatrics over night with them'</i> (Parent A).</p> <p><i>'When they're on children's you can have home food and warm it up in the parent's section and although she was told you can have pizzas and this and that...there's not anyone to heat it up, that's an important part of their care that they've got to have such high nutritious food'</i> (Parent B)</p> |
| | e) Opportunities to become familiar with a new setting | <p><i>'[The social worker] showed me around once but I didn't know about these [clinic] rooms and how it worked or anything... With the transition clinics, why not have one over there [adult hospital]... so you're used to the rooms and everything'</i> (E)</p> <p><i>'I came over to look around... but I was always taken through the staff entrances, so I was thinking how do I get there as a patient?'</i> (B)</p> <p><i>'Have some clinics over here [adults] as well as over there so you're more familiar with the surroundings. If you're more familiar you're always going to feel more comfortable.'</i> (Parent B)</p> |
| Changes in the nature of relationships with healthcare professionals | a) Perceptions of a less personable in adult services | <p><i>'I had a good relationship with everyone on the children's CF team... you don't feel like you're one of many, they take the time to talk to you and you can make other conversation other than hospital talk whereas at the BRI they just come in and see me for 20 minutes and then they're happy to disappear...it's my life'</i> (A)</p> <p><i>'When I was over there [children's service], I used to ring my CF nurse and she talked to a doctor, I'd tell them I needed to come in and over here you've got to ring the office, if you can't get through then you've got to wait'</i> (E).</p> |

Table 2: Themes and key quotations from the data cont.

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| | | <i>'Sometimes I ring the CF office and I leave a message and no one will get back to me' (A).</i> |
| | b) Getting to know the individual | <p><i>'Everything comes back to listening, understanding me.' (E)</i></p> <p><i>'She was so very very ill and we've been well looked after then. The Psychologist came to see us and we were always given time to talk if we needed to and never felt we had to be out of the way.' (Parent B)</i></p> <p><i>'You have to build a relationship with them, although they have your notes, that's just notes, they would have to get to know you as a person as well' (A).</i></p> <p><i>'I felt they knew me already [the consultant] remembered things I'd said in my transition appointment so I think they did know quite a bit about me before I went'. (C).</i></p> <p><i>'It is important to have the opportunity to meet the person as a person without CF being part of it... (Parent A).</i></p> <p><i>'...what I'm like so they know more about me, what I do, my personality so they know how to come across me. They'd have to meet me to see what I'm like... I'd want them to get close to be my family as well.' (D)</i></p> |
| | c) Continuity of relationships and care | <p><i>'They should have done it with both of them and for them to watch what's going on to see how you react to things, then we can talk about stuff.' (D)</i></p> <p><i>'It was good cos I had physio come in when I was having the treatment session so she could see what the treatment is that I have done' (B)</i></p> <p><i>'Seeing more of the adult team alongside the children's teams that would probably be better' (Parent B)</i></p> <p><i>'Although we don't see the children's hospital staff anymore, we know they work as a big team so that's important that there are still links with the two rather than just a cut off point I think that's so important to know' (Parent C)</i></p> |

Table 2: Themes and key quotations from the data cont.

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| Transition as a condensed process in the context of adolescence | a) Suddenness of transfer | <p><i>'You think you're going to stay there [Children's Hospital]... You don't get prepared until you're 17, they say right you're 17, you've got to go...you're smack bang over here...you have to deal with it yourself.'</i> (E)</p> <p><i>'When I had my first [adult] appointment I thought that was just an appointment to meet everybody... I didn't know that was going to be my last appointment with [paediatric consultant]... It was a complete shock after spending 18 years with the same people.'</i> (A).</p> <p><i>'She went from being a child in the children's hospital and having her regular routine of school and college to suddenly being taken out of her comfort zone in the children's hospital'</i> (Parent A).</p> |
| | b) Starting preparation early | <p><i>'If they want you to come over when you're 18, they should start preparing you when you're 16, start getting you ready.'</i> (E)</p> <p><i>'I think talking about you needing to move sooner...Encouraging children to want to take over their own care because then it won't be as much a shock when they get to adults and they get told they need to do it...At 13 or 14, start off with just tablets but still having the parents there to make sure they do it'</i> (B).</p> |
| | c) Other pressures and changes during transition | <p><i>'when you become 16/17 you've got to start making decisions, so you're making decisions about your future and you see everyone else making decisions and plans to go away to University...'</i> (Parent A)</p> <p><i>'at the same time the disability living allowance was up for review so we had over a year of battling...so we went from having a very comfortable environment where we felt safe in the paediatrics to suddenly having to address the transition, the movement from school and college and possibly losing benefits'</i> (Parent A).</p> <p><i>'Certainly when they're around the age of 15 or 16 they've got quite a lot on their plate cos they're studying for exams and things so they're having to take a lot of responsibility in that way.'</i> (Parent B)</p> |
| | d)Valuing the wider support around transition | <p><i>'We've got the social worker and she's really good, she's helped with a lot of stuff like getting the benefits I'm entitled to... I've just moved out actually into my own place so she helped with that... You just give her a text.'</i> (B).</p> <p><i>'I'm getting married this year and they've been really supportive of that by making sure I'll be well enough... preparing me to be in hospital before so I don't need to be in when I get married...I've discussed about maybe having children in the future with someone'</i> (B)</p> |

Table 2: Themes and key quotations from the data cont.

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| | | <i>'[Young person] wasn't able to go to school full time so they liaised well with the school to get things in place so she had somebody to come and give her home schooling.'</i> (Parent B). |
| Changing roles in healthcare | a) The perceived expectation to be independent | <p><i>'When I was moving to adults they said you need to be doing your own home IVs, we expect this of you' (B)</i></p> <p><i>'As soon as you get to teenager they expect you to do it more yourself, take tablets on your own, do nebulisers on your own...In adults they don't do anything for you, you have to do everything by yourself.'</i> (D)</p> <p><i>'It's scary, everyone relies on you to do it, they don't come in to remind you, you've just got to do it.'</i> (D)</p> |
| | b) Staff encouraging motivation for independence | <p><i>'The consultants in the paediatrics were very keen to say to [yp] why don't you come in on your own for a bit then mum can come and join you afterwards.'</i> (Parent A).</p> <p><i>'They did work hard in trying to encourage [yp] to be more independent before she left the paediatric service but it doesn't always come easy.'</i> (Parent A).</p> <p><i>'Encouraging you to want to do your own medication and stuff because I know that a lot of children aren't. Encouraging children to want to take over their own care' (B).</i></p> |
| | c) Gaining more responsibility | <p><i>'I've been doing my care since I was quite young...the first time I remember doing it was probably when I was 6...I think you need to be able to do it, especially if you want to be able to move out and live a proper normal adult life... That's why I can move out cos I can do all my own care.'</i> (B)</p> <p><i>'When you go from the paediatric service to the adult service, the parents are asked to take a step back...the young person has to manage not only the move but the whole interview process independently' (Parent A)</i></p> <p><i>'You say it better than I do, I find it hard to find the words. I get frustrated.'</i> (A).</p> <p><i>'They use big words with me now... Sometimes it's a bit like yeah whatever I don't have a clue what that means...'</i> (B)</p> <p><i>'Previously in the paediatric set up I'd go in and I'd have very clear idea of what we needed to talk about... As an adult you can get the information much easier and much quicker... more specifically...but when the young person goes into the adult service I don't do the talking (Parent A).</i></p> |

Table 2: Themes and key quotations from the data cont.

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| | d) Difficult for parents to pass over control | <p><i>'Sitting back and listening to what [my daughter] says I'm thinking she hasn't mentioned what happened two weeks ago... she's quite happy for me to do a lot of the talking even now and I try very hard not to. But often what she doesn't see as relevant, it's very relevant to me' (Parent A).</i></p> <p><i>'[in paediatrics] a lot of parents stay on the ward so when the doctor comes round the parents are there so we tend to do the talking... if they [had time] on their own it would just encourage them to be more free with their expression.' (Parent A).</i></p> <p><i>'everyone looks to her to answer her own questions which is fine, it's as it should be...It's always a bit daunting first of all, but you have children not to keep them under your wing but to bring them up to be independent' (Parent B)</i></p> |
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1) Moving on from the familiarity and security of the children's service

A strong theme to emerge was the bond between the families and the paediatric team. Participants described feeling comfortable in the service and viewed the team as family. This strong bond meant that the prospect of leaving was difficult. Perceptions of feeling alone and abandoned on the adult ward followed for some..

a) Anxiety and reluctance to move on.

As a result of this bond, strong views were expressed about moving to the adult service. Some did not want to believe they were going to leave the children's service, perhaps indicating a lack of knowledge about the adult service or a lack of opportunities to properly consider and discuss what being in adult services would be like.

One young person expressed her perceived unfairness of moving and conveyed some anger; her transition was a decision that had been made for her and she had no control over this major change happening. With the prospect of change came anxiety for some about possible deterioration in health and important details being lost, however a mother expressed how these worries and anxieties were unfounded.

b) Stepping out of trusted family into the unknown

The paediatric team were referred to as being like family by nearly all participants. Most had known the team since infancy, therefore had a long shared history with them and a trusting relationship. Stepping out of this family into the unknown was daunting for some. This was felt as much by the parents as the young people. One parent expressed the loss of emotional support. Having to deal with new people was stated as the most worrying part of transition for one girl who was due to transfer soon.

c) Not fitting in on the adult ward

The contrast experienced between the children's and adult ward was evident. A sense that the young people did not fit with this new environment, seeing themselves as different from the other patients was conveyed. The participants

talked about not having the same amount of informal contact with staff and therefore feeling alone and isolated on the adult ward. One young person suggested that having a night on the adult ward before moving to use adult services would be helpful.

d) Parents withdrawing comfort on the adult ward.

When the young people started to stay on the adult ward, it was also difficult for some parents to not be with their child and offer the same degree of comfort. This came suddenly for one parent who talked about how hard it was to leave her daughter and suddenly start seeing her as an adult. One parent had concerns about not being able to provide warm nutritious food to her daughter when on the adult ward in the way she had been able to in the children's hospital.

e) Opportunities to become familiar with the new setting

Several young people and parents spoke of being shown around the adult hospital prior to their transfer. It seemed that it would be more valuable to have appointments in the adult hospital to build better familiarity with the processes and decrease the amount of anxiety about the change.

2) Changes in the nature of relationships with health care professionals

Some young people perceived a less individualised person-centred approach in the adult service with some feeling that professionals did not listen to them. They highlighted the importance of time to get to know their new health care team and for them to get to know the young person, beyond their illness.

a) Less personable in adult services

Some young people felt more rushed in adult clinic appointments and with that had a view that the health professionals did not see and care about them as an individual beyond their medical needs. Young people also noted a barrier in contacting CF staff in adults compared to being able to contact a children's CF nurse directly in the paediatric service.

b) Getting to know the individual

The importance of the young people and their families feeling listened to was expressed. Getting to know the young person beyond their medical notes as individuals was important to the young people and their families. One young person recalled the adult consultant remembering details from what she had talked about in her transition clinic appointment, which she valued; a demonstration of person centeredness.

Prior to starting to use adult services, one young person explained that the most important information for the new team to have was regarding who she was as a person. She hoped that the new team would become like a family in a similar way to the paediatric team.

c) Continuity of relationships and care

The shared clinics prior to transfer were an important step to get to know the new team. It seemed important for some young people that the adult team watched the treatment. It was important for families to see the two teams working alongside each other and for this to continue post-transfer, emphasising the continuity of care.

3) Transition as a condensed process in the context of adolescent development

Adolescence is a gradual developmental stage in which young people face many changes and challenges. Within this, the transition to using adult services came abruptly to some young people and so seemed like a condensed process of growing up. Some expressed starting transition earlier would be helpful.

a) Suddenness of transfer

Transfer was perceived to come abruptly for some who expressed a sense of shock when they were expected to start using adult service. Suddenly the supportive network around them disappeared. Along with the abrupt change came a sense that the young people had suddenly changed from being children to adults.

b) Starting the preparation early.

Some young people expressed that starting preparation earlier would be preferable, with suggested ages ranging from 13-16. One young person explained how this would lessen the shock of the change and suggested that small steps are made early to increase independence in healthcare, such as them being responsible for taking tablets.

c) Other pressures and changes during transition

At the time of transferring to adult services, young people and their families were facing other challenges including making difficult decisions about the future, experiencing changes to benefits and having exams at school and college. The big life change of transferring to adult services takes place in a context of challenging time of life.

d) Valuing the wider support around transition.

Some young people and parents spoke about valuing the wider support at this time including benefits, life events and education. The social worker attached to the team was a valuable source of support at this difficult time.

4) Changing roles in healthcare

The young people spoke about the experience of taking on more independence in healthcare and the perception that the adult service expected this of them, for example, in the communication during clinic appointments.

a) The perceived expectation to be independent

When the young people started using adult services they perceived an expectation of them to be reasonably independent in their health care. Participant D, who was due to transfer, held the belief that the adult team expected her to do everything independently and was scared about the responsibility that came with this.

b) Staff encouraging motivation for independence

The way that the paediatric staff encouraged independence was highlighted by some, for example by asking the young person to have some time alone with the

consultant. One young person suggested that encouraging motivation was an important factor so that the patients wanted to take some responsibility.

c) Taking on more responsibility

One participant explained that she had had become independent in some aspects of her healthcare early and spoke about the positive impact of this on her life. She saw it as necessary if she wanted to live an independent adult life.

The process of taking more of a communication lead during appointments was spoken about. For some, this posed difficulties if they did not understand what was said by the health professionals during appointments. Some young people believed their parents to be more skilled to take this lead. A parent echoed this idea about them having more expertise in managing the communication, therefore this shift was more difficult.

d) Difficult for parents to pass over control

As the young person gained more independence and control of their healthcare, the parents felt a need and expectation to step back. Some found this difficult to do. For example, one parent expressed that she may think information is relevant to report that the young person does not. Another parent described this process as daunting but necessary.

Discussion

Making the transition into adulthood can be greatly affected by the impact of chronic illness (Stam et al., 2006). Moving onto using adult healthcare services brings up many issues for both the young people and their parents and many services are focusing on improving preparation and reducing the risk of health deterioration. Good practice guidelines regarding transition emphasise the collaborative development of a transition plan including aspirations and goals of the young person (DoH, 2006).

This qualitative study aimed to explore the experiences of young people and parents in their transition to using adult CF services. Despite the small sample of participants, the themes that emerged from this study indicate how this process is complex, bringing up many challenges for families and thus requires careful consideration and preparation. Interviews with five young people and three parents identified four key themes: moving on from the familiarity and security of children's services; changes in the nature of relationships with health care professionals; transition as a condensed process in the context of adolescent development; and changing roles in healthcare. Such themes echo, to some extent, previous qualitative work in the field included in the guidance produced by RCPE (2009).

A strong theme to emerge was the close relationships that families had with the paediatric team, having known them for many years. The term "family" was used several times, having connotations with familiarity, safety and endurance. The prospect of losing this established safety network and stepping into the unknown will inevitably create anxiety for families, as reflected in the interviews; anger, anxiety and avoidance were all conveyed. Concerns about the young person's health deteriorating, the need to build new relationships and a lack of control around transferring were all evident. This strong emotional response is likely to have an effect on how the families view adult services and how open to transition preparation they are. Perhaps families cope by being resistant or avoidant when considering transition which creates a barrier to preparation. The perception that the move came unexpectedly and suddenly for some is perhaps another indication of how they view transition and their lack of preparation.

The strong attachment to the paediatric team will impact on the formation of new relationships. A stark contrast was conveyed between the relationships with the paediatric team and that of the adult team and it became clear that developing new trusting relationships with the adult team was a central aspect in transition.

A change in culture to a more "illness centred" approach, as perceived by some participants, has been highlighted in previous studies and identified as a barrier to successful transition (Reiss et al., 2005; Viner, 1999). Changes in staff to

patient ratio in the adult service may play a part in this, however it is important for services to consider the factors that impact this perception and how patients may be prepared to deal with inevitable changes.

Most young people interviewed mentioned the valued existing practices of transition clinics and visits to the adult hospital. It seems important for the young person to experience the adult service as a patient, attending some clinics based in the adult service prior to transferring. This would help build familiarity and confidence with the process and the team. Some participants expressed having the adult team more involved during transition appointments, e.g. observing their treatment, and getting to know the young person as an individual would be valuable.

It became clear that parents were equals in the transition and their needs should also be addressed in preparing for the change to the adult service. Parents may feel that expectations of their role abruptly change and may feel reluctant to pass over control, take a step back in communication, and withdraw some aspects of the nurture that they were able to provide in the paediatric settings. Parents need adequate preparation and support around the emotions that transition brings about, to consider what transition means to them as a parent and how their responses may influence their son or daughter's transition.

Gradually moving away from parental dependence and forming an identity has long been considered part of moving into adulthood (Erikson, 1963). However transition to adult services appeared to come abruptly for the young people interviewed and with it came strong perceptions of the expectation that the young people be more, or totally, independent in their healthcare. This highlights the need to ensure that transition is viewed as a process, starting early. Some healthcare literature has highlighted that in reality the move away from parents in young adulthood is rarely a linear process (Valentine, 2003) and that choice and fluidness regarding parental involvement should be emphasised (Allen et al., 2011). Indeed, previous research has shown the importance of the ongoing role of parents in self management of CF post-transition (Brumfield & Lansbury, 2004).

Service recommendations

A number of service recommendations for the management of transition may be gleaned from the experiences captured by the present study. A core theme that appears to permeate all others is the strong attachment to paediatric team and the anxiety about change. How the service manages this separation and the transition to a new team is a necessary area for exploration. It is important that the paediatric team attend to the emotional impact of transition for the young people and their family, explore what transition means to them and specific fears they have to help reduce anxiety, resistance and increase their openness to new relationships.

Practices that can help bridge the gap, increase familiarity and reduce anxiety should be implemented. For example, it is recommended joint clinics based in the adult hospital start early in the transition process. It seems important that the adult team are introduced early so that relationships can begin to be established with the young people and their families prior to the transfer. This may also improve continuity of care and address the abruptness of transfer that was raised. It is recommended in the guidelines that transition should start to be discussed when the patient is aged 13-14, although this is flexible.

It is also recommended that the parents have their own targeted transition support. The paediatric CF team already hold regular parent evenings. Building on this practice, it may be useful for the adult CF team to host some parent evenings to cover some of the common issues that parents face when moving onto adult services and be relaxed and informal in nature. This would provide the parents with an opportunity to start building relationships with the adult team, as it was highlighted by parents that moving away from the longstanding trusting relationships with the paediatric team was difficult.

Goal setting with the young person is included in the good practice guidelines (DoH, 2008). It appears that the focus of this is on healthcare independence with little attention to wider issues around how the young people want to manage their health care, for example, how much involvement they want their parents to

have. It may be helpful for the young people to explore this early, possibly at the time of the first transition clinic, and also discuss the implications of self-management. Some young people may want to be able to take a lead in appointments but face barriers e.g. their perceived communication skills, which can then be addressed in a timely manner.

Dissemination to the service

The themes were presented and discussed to the transition steering group and to the adult and paediatric CF teams. Recommendations were presented as preliminary ideas to then be elaborated. The adult team agreed to hold parents' evenings focused on transition and based on some of the themes that have emerged. A small working group took on the task of planning this.

Areas of further research

The themes identified in this study reflect many of the issues identified in previous literature, highlighting that current practices may be limited in addressing the challenges around transition. A major theme that emerged was strong bond held with the paediatric team and the anxiety about change. Further research focused on interventions aimed at reducing this anxiety would be useful.

Limitations

A small sample size limits the generalizability of these themes although the themes are supported by literature in the field. All the participants in this study were female. It is possible that different issues emerge for males, indeed some literature has identified gender differences in healthcare transition outcome (e.g. Lotstein et al., 2009). The young people may not have been completely truthful about their experiences due to social desirability, although having a researcher independent of the CF teams may have helped with this. All participants were volunteers and their opinions may differ from those who chose not to take part. All the participants were White British ethnic origin, therefore other issues may come up for those from a different culture. Only one participant was approaching transition therefore the data may not adequately capture the anxieties and concerns of those approaching transition.

Conclusions

The experiences of healthcare transition were explored with five young people with cystic fibrosis and three parents. The themes that emerged highlighted the complex nature of the transition process. The challenge for both patients and parents in moving on from a safe and familiar context should not be underestimated. The themes highlighted a need for families to have the opportunity to build relationships with the adult team earlier and address issues that may arise in a timely manner.

References

- Allen, D., Channon, S., Lowes, L., Atwell, C. & Lane, C. (2011) Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. *Diabetic Medicine* 28(8): 994-1000 doi: 10.1111/j.1464-5491.2011.03310.x.
- Badlan, K. (2006) Young people living with cystic fibrosis: an insight into their subjective experience. *Health and Social Care in the Community* 14(3): 264-270 doi: 10.1111/j.1365-2524.2006.00619.x
- Braun, V & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2): 77-101 doi: 10.1191/1478088706qp063oa
- Brumfield, K., & Lansbury, G. (2004). Experiences of adolescents with Cystic Fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation*, 26(4), 223-234. doi: 10.1080/09638280310001644924
- Conway, S. P. (1998). Transition from paediatric to adult-orientated care for adolescents with cystic fibrosis. *Disability and Rehabilitation* 20(6-7): 209-216.

Department of Health (2006) *Transition: Getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services*, Department of Health, London.

Department of Health/Department for Children, Schools and Families (2008) *Transition: Moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*, Department of Health/Department for Children, Schools and Families, London.

Dodge, J. A., Lewis, P. A., Stanton, M., & Wilsher, J. (2007). Cystic fibrosis mortality and survival in the UK: 1947-2003. *European Respiratory Journal* 29(3): 522-526. doi: 10.1183/09031936.00099506

Dovey-Pearce, G., Hurrell, R., May, C., Walker, C., & Doherty, Y. (2005). Young adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health & Social Care in the Community* 13(5): 409-419. doi: 10.1111/j.1365-2524.2005.00577.x

Erikson, E. H. (1963) *Childhood and Society*. Publisher: Norton; New York, NY, USA

Foster, C., Eiser, C., Oades, P., Sheldon, C., Tripp, J., Goldman, P., Trott, J. (2001). Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts. *Child Care Health and Development* 27(4): 349-364. doi: 10.1046/j.1365-2214.2001.00196.x

Lotstein, D.S., Ghandour, R., Cash, A., McGuire, E., Strickland, B. & Newacheck, P. (2009) Planning for Health Care Transitions: Results from the 2005-2006 National Survey of Children with Special Health Care Needs. *Pediatrics* 123 (1): e145-152 doi: 10.1542/peds.2008-1298

- McDonagh, J.E. (2006) Growing up ready for emerging adulthood. An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities. London: Department of Health.
- Reiss, J.G., Gibson, R.W. & Walker, L.R. (2005) Health care transition: youth, family, and provider perspectives. *Pediatrics* 115 (1): 112-120 doi: 10.1542/peds.2004-1321
- Royal College of Physicians in Edinburgh (2009) *Think Transition: Developing the Essential Link Between Paediatric and Adult Care*. Edinburgh: Royal College of Physicians in Edinburgh.
- Shaw, K.L., Southwood, T.R., McDonagh, J.E. (2004) Improving the quality of life for adolescents with juvenile idiopathic arthritis: results of a postal survey. *Rheumatology* 43: 211–219.
- Stam, H., Hartman, E. E., Deurloo, J. A., Groothoff, J., & Grootenhuys, M. A. (2006). Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *Journal of Adolescent Health* 39(1): 4-13. doi: 10.1016/j.jadohealth.2005.03.011
- Valentine, G. (2003) Boundary crossings: transitions from childhood to adulthood. *Children's Geographies* 1: 37–52 doi: 10.1080/14733280302186
- Viner, R. (1999) Transition from paediatric to adult care. Bridging the gaps or passing the buck. *Archives of Disease in Childhood* 81: 271–275 doi:10.1136/adc.81.3.271

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Main Research Project: Social anxiety and self-perceptions of social performance in adolescents and young adults with high functioning autism spectrum disorders

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Internal supervisor: Dr. Ailsa Russell

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Journal targeted for publication: *Journal of Autism and Developmental Disorders*
(see appendix E).

This journal was selected due to it being the leading peer-reviewed journal in the area of autism spectrum disorders, which has published multiple previous articles relating to social anxiety and loneliness in this population.

Abstract

This study aimed to 1) investigate if adolescents and young adults with autism spectrum disorder (ASD) who are high in social anxiety underestimate their social performance when compared with those low in social anxiety, and 2) investigate the association between social motivation and social anxiety. Participants (n=20) aged 14-21 years completed measures of social anxiety, loneliness and social satisfaction before taking part in a video-recorded group discussion. Self and observer ratings of social performance were analysed. Results revealed that participants high in social anxiety rated themselves significantly poorer than did observers. The interaction between social anxiety group and rater was non-significant. Loneliness significantly correlated with social anxiety. This study highlights how cognitive factors may be involved in social anxiety for young people with ASD and discusses implications for psychological intervention.

Keywords: autism, ASD, social anxiety, loneliness, adolescence

Introduction

Autism Spectrum Disorder (ASD), according to DMS-V, is defined by qualitative impairments in social communication and social interaction across multiple contexts and restricted repetitive behaviour patterns (APA, 2013). In terms of the impact on social functioning, the core deficits of ASD fall into the domain of social-emotional reciprocity, which may include a paucity of sharing ideas, interests and emotions, and reduced back and forth communication. There can also be reduced understanding and use of non-verbal communication behaviours, such as eye contact and body language, as well as difficulties in developing and maintaining relationships. Such social interaction difficulties may lead people with ASD to be rejected by peers and experience anxiety or discomfort in social situations. Social anxiety has been shown to be significantly higher in people with ASD than typically developing populations (White et al., 2009).

Social anxiety disorder in typically developing children and adolescents

Social anxiety is a significant fear of social situations characterised by worries about negative evaluation by others of social performance. Social anxiety disorder is reported to have a prevalence of around 7% in children and adolescents (e.g. Beesdo, 2009) and typically increases during adolescence when esteem becomes increasingly derived from peer relationships (Carr, 1999). Recently there has been increased attention given to the cognitive aspects of social anxiety in children and adolescents. Hodson et al. (2008) provided support for the application of the empirically-derived cognitive behavioural model of social anxiety (Clark and Wells, 1995; Clark, 2001) to children and young people, which includes negative social cognitions, self-focused attention, safety-seeking behaviours and pre- and post-event processing.

Further support for cognitive aspects of social anxiety in young people comes from studies that have shown that children high in social anxiety rate themselves more poorly on measures of social performance compared to those low in social anxiety despite there being no difference in objective observer ratings. This would suggest that some distortion in their self-evaluation of social skills may be related to social anxiety (Cartwright-Hatton et al., 2003, 2005). Authors argue that treatment which emphasises learning or improving social skills may be counterproductive by maintaining individuals' inaccurate beliefs about their deficits in this area. Treatments derived from the cognitive behavioural model of social anxiety (Clark and Wells, 1995; Clark, 2001) emphasise instead the role of cognitive factors in maintaining social anxiety. Patients are encouraged to evaluate thoughts and beliefs in an experimental fashion, using the results to re-evaluate and reconsider their internal experiences which ultimately drive their behavioural response.

Social Anxiety in ASD

Individuals with ASD are more likely to be diagnosed with anxiety and mood disorders. A recent campaign by the National Autistic Society (NAS) reported that 71% of children with autism have co-occurring mental health problems, calling for services to understand and adapt to meet this need (NAS, 2010). Anxiety has been reported in 40-45% of children with ASD (White et al., 2009)

with social anxiety disorder being the most prevalent disorder among young people and adults with ASD who do not have co-occurring intellectual impairment (Bellini, 2004). For example, Kuusikko et al. (2008) found that 57% of a sample of children and adolescents with high functioning ASD reported clinically significant social anxiety. Similarly, Bellini (2004) identified 49% of a sample of 41 high functioning adolescents with ASD as self reporting clinically significant social anxiety. In a population-derived sample of 10 to 14 year-olds, Simonoff and colleagues found that social anxiety disorder was one of the most common comorbid diagnoses found in 29.2% of the sample. Despite this, few epidemiological or clinical studies have investigated social anxiety in ASD further.

There has been some concern as to whether there has been an over estimation of social anxiety disorder due to overlapping constructs and whether social anxiety should be viewed as part of ASD due to the high rate of co-occurrence. White et al. (2012) explored the overlap between the Social Phobia Anxiety Inventory-23 (Roberson-Nay et al., 2007) and the Autism Spectrum Quotient (Baron-Cohen et al., 2001) in 623 people aged 18-22 years. The analysis revealed separable but highly correlated factors and provided some evidence for true comorbidity. The relationship between symptoms of ASD and social anxiety disorder were significant and maintained when social components of ASD were removed.

Anxiety is thought to exacerbate the effects of the social impairment and social functioning central to ASD (White et al., 2010). Therefore, understanding the nature of social anxiety in ASD may aid the development of effective interventions and alleviate this additional source of disability and distress. Several models have been suggested to explain the development of social anxiety disorder in ASD. These implicate factors such as increased physiological arousal, social withdrawal/behavioural inhibition, limited opportunities to interact, reduced social skills and negative peer interactions. Bellini (2006) examined the contribution of social skills deficits and physiological hyper-arousal in the development of social anxiety in adolescents with ASD finding that both these factors predicted social anxiety. Bellini proposed a model of the development of

social anxiety in ASD, explaining that a temperament marked by heightened physiological arousal makes an individual more overwhelmed by social interaction. This leads to avoidance of such situations, limiting the opportunity to develop and practice social skills resulting in more negative peer interactions and further increased arousal (Bellini, 2006). Despite this developmental model being frequently cited, there is a lack of empirical evidence supporting this pathway and the mechanisms involved. There has been a lack of attention paid to the possible role cognitive factors, such as appraisals and self-focused attention, may play, which in typically developing populations is emphasised to be at the core of social anxiety.

Social Motivation

The prevalence of social anxiety is particularly high in those with ASD without accompanying intellectual impairment, or high functioning ASD, (Bellini, 2004; Farrugia and Hudson, 2006; Kuusikko et al., 2008) possibly due to higher insight and self-awareness. It is possible that individuals with high functioning ASD have greater social motivation coupled with an awareness of their social communication difficulties (White et al., 2010). Studies have found that many people with high functioning ASD are socially motivated and desire a higher degree of interpersonal relationships (Bauminger and Kasari, 2000; Muller et al., 2008; White and Roberson-Nay, 2009). Social motivation has been operationalised by measuring loneliness, due to loneliness being reported to be the strongest drive in typically developing children to take part in social interaction (Asher et al., 1990). Loneliness is associated with an undesired isolation and negative feelings (Bauminger et al., 2003) which may be reflective of the degree of their desire for greater or different peer relationships. Children with autism have reported a higher degree of loneliness when compared with typically developing peers (Bauminger et al., 2003). The dissatisfaction which is implicit within the concept of loneliness would contradict ideas that people with ASD have a preference for aloneness and instead face barriers to social relationships despite their motivation. White and Roberson-Nay (2009) found that youth with ASD (aged between 7 and 14 years) with elevated levels of anxiety reported greater social loneliness than those who reported lower levels of anxiety. White et al. (2012) hypothesised that as individuals with high functioning

ASD reach adulthood, social motivation may be a primary ingredient contributing to anxiety, suggesting an important cognitive component.

Treatment approaches for social anxiety in ASD

There is emerging evidence for the use of cognitive behavioural therapy (CBT) for children and adolescents with ASD and anxiety (Sofronoff et al., 2005), although very few trials have evaluated treatment interventions specifically for social anxiety in adolescents with ASD. Wood et al. (2009) reported a randomised controlled trial for CBT for anxiety in children aged 7-11 with ASD. A large proportion of participants presented with social phobia. The intervention, which contained elements such as affect recognition, cognitive restructuring and behavioural experiments alongside parent-training and school consultation a high level of positive treatment response. White (2010) outlined a CBT intervention which targets both social skills and anxiety. A pilot study of 30 individuals indicated a decline in anxiety symptoms which did not reach significance. Interestingly, a social skills intervention that did not directly target anxiety showed a decrease in social anxiety compared to waitlist control (Schohl et al., 2014), which authors hypothesised was attributable to increased knowledge and confidence in social situations. Social anxiety was markedly higher at pre-intervention in the experimental group and it was not clear whether this was clinically significant.

It is clear that more research is needed specifically looking at treatment of social anxiety in adolescents with ASD. If a similar cognitive distortion in social performance is evident in adolescents with ASD, as was found by Cartwright-Hatton et al. (2003, 2005), this may have implications for the incorporation of social skills training. It is likely that a label of ASD and the focus on social skills deficits may negatively influence an individual's appraisal of their social performance further exaggerating a distortion.

Rationale and aims

This study asks whether the previously reported findings of a cognitive distortion in self-assessment of social performance in typically developing young people with social anxiety (Cartwright Hatton et al., 2003, 2005) also exists in young

people with ASD and social anxiety. Previous research in young people with ASD (e.g. Bellini, 2006) investigating possible links between social skills deficits and social anxiety used a self-report measure only. The present study will then compare observer with self-ratings of social skills to better understand the role of self-appraisal in social anxiety. Furthermore, as White and colleagues suggest, social motivation may also be a primary factor distinguishing those with high social anxiety. Therefore, this study will also consider this factor in adolescents.

Hypotheses

- 1) There will be a significant discrepancy between self and observer ratings of social performance in young people with a diagnosis of ASD without accompanying intellectual impairment and high levels of social anxiety when compared to young people with a diagnosis of ASD and low levels of social anxiety
- 2) Social anxiety in young people with a diagnosis of ASD without accompanying intellectual impairment will be positively correlated with loneliness and negatively correlated with social satisfaction.

Method

Design

This study took a within subjects cross-sectional design.

Participants

Participants were recruited through specialised educational provisions and social groups specifically for young people with ASD. Inclusion criteria were that the participants were in full time education, aged at least 13 years, due to the increased occurrence of social anxiety from this age, and not older than 21 years. Participants were in full time education and had a diagnosis of ASD without recognised intellectual impairment, as confirmed by the professionals who worked with them. All participants had English as their first language. Initially the study was to include participants up to 18 years old, however due to

the age range at the education provisions targeted, it seemed inappropriate to exclude those between aged 18 to 21 years.

Power analysis

An a priori power analysis using GPower indicated that 22 participants would be needed in each group to have an effect size of 80% for detecting a medium effect, a total of 44 participants.

Measures

The Social Anxiety Scale for Adolescents (SAS-A; La Greca, 1999).

The Social Anxiety Scale for Adolescents is an 18 item self report measure with four additional filler items. A three factor structure has been consistently revealed in studies with each factor demonstrating good internal consistency (La Greca and Lopez, 1998): fear of negative evaluation (FNE, 8 items, $\alpha = 0.91$), social avoidance and distress in new situations (SAD-new, 6 items, $\alpha = 0.83$), and social avoidance and distress more generally when in the company of peers (SAD-G, 4 items, $\alpha = 0.76$). Construct validity was further supported by a larger study of American adolescents aged 11 to 18 years (Inderbitzen-Nolan and Walters, 2000) A total score of 50 or above is considered as clinically significant social anxiety (La Greca, 1999). Test-retest reliability has been demonstrated over two months and six months (Vernberg et al., 1992) with FNE demonstrating the highest test-retest correlations. This measure was selected due to its clear factor structure, which would allow a greater investigation into social anxiety, and its previous use in studies of social anxiety in young people with ASD (Bellini, 2004, 2006). The child version of this measure was used in the aforementioned study by Cartwright-Hatton (2005). Although the SAS-A was developed and validated for adolescents up to the age of 18 years, it was deemed appropriate for use with the present sample (aged 14-21), however post hoc analysis was undertaken to control for any effects of age.

Asher Loneliness Questionnaire (Asher et al., 1984).

The Loneliness Questionnaire, originally developed by Asher et al., (1984) is a 24 item measure of loneliness. 16 items focus on feelings of loneliness and eight items are filler questions. The measure has been used with young people with ASD (Bauminger and Kasari, 2000). Bauminger et al. (2003) modified the questionnaire to further distinguish between social (perceived lack of social involvement with peers) and emotional loneliness (feelings of isolation and lack of affective bonding) adding six new items. This modified scale has demonstrated high internal consistency in a sample of individuals with high functioning autism aged 8 to 17 years ($\alpha = 0.92$).

Social Satisfaction Items.

Two questions were developed for the purposes of the present study to enquire about social satisfaction: (i) *How satisfied are you with the amount of friends you have?* and (ii) *How satisfied are you with the quality of the friendships you have?* These questions were presented in a written format and participants asked to rate them on a 5 point Likert scale with 1 corresponding to being very dissatisfied and 5 corresponding with very satisfied.

State Anxiety Scale.

A visual analogue scale to measure state anxiety during the group discussion was developed (Appendix I). Participants were asked to indicate the level of anxiety they experienced in the social performance task on a 10 point scale (0= no anxiety at all, 10= extreme feelings of anxiety). Numbers were clearly referenced along a line which was coloured from blue (0) to red (10).

Performance Questionnaires.

The original performance questionnaires were developed by Cartwright-Hatton et al. (2003, 2005) and modified slightly for this study (Appendix K). The original performance measures, of which there are separate self and observer versions, comprise of eight questions scored on a four point scale. These questions are in relation to micro-behaviours (e.g. how loud and clear was your voice?), nervous behaviours (e.g. How much did you blush?) and global impressions (e.g. how friendly did you look?). The original performance questionnaires have demonstrated an alpha of 0.74 for the child (self-rated) version and 0.91 for the

observer version. The questionnaires were modified slightly for this study (see appendix B) with the addition of an item relating to use of eye contact. Items were presented as statements rather than questions and participants asked to indicate how much they agree or disagree with the statements using a four point scale. The items are totalled, with some items reverse scored, giving participants a score out of 36. The higher the number the more favourable rating of social performance.

Procedure

The study was approved by the University of Bath Psychology Ethics Committee (Appendix F). Approval was also gained from the relevant county council (Appendix G). Participants were given a written project information (Appendix H) with a separate version for parents (Appendix I). Parental consent was obtained for all participants under the age of 18 years. All participants gave written informed consent immediately prior to taking part.

The study was carried out in the education or social group setting. Participants completed the SAS-A, Loneliness Questionnaire and social satisfaction items prior to the group task. Participants then took part in the social performance task. This was a group discussion following the showing of a short piece of film available from *YouTube* entitled '*Channel 4 Paralympics - Meet the Superhumans*' (C4 Paralympics, 2012). This piece of film was selected due to the recent awards it had received and deemed to have a content that was neutral enough to appeal to a wide audience as opposed to being related to any particular interests. Groups consisted of between 3 and 5 participants and the researcher (HW). A research assistant was also present for groups of < 3 participants. The research assistant had some involvement in the discussion and was present to increase the social demand by increasing the number of people present. During the discussions the researchers were blind to participants' responses on the measures.

After watching the short film, participants were asked what they thought about the film, if they thought it was effective and why. The conversation was free to follow any relevant areas of discussion. Each person was invited to contribute to

this discussion, however there was no pressure to do so if they did not want to speak. Discussion lasted approximately 10 to 15 minutes and were recorded on a digital camcorder.

Following the discussion, participants were asked to complete the performance ratings and state anxiety scale. Two researchers later watched the footage and completed the observer ratings, blind to the participants' questionnaire scores and self performance ratings. Observer ratings were discussed and a consensus reached where there was inter-rater discrepancy

Data analysis

Data were analysed using IBM SPSS version 21. Chronbach's alpha coefficients were calculated to assess the internal consistency of the measures and the data were explored for distribution. To investigate hypothesis 1, participants were grouped into high and low social anxiety according to their score on the SAS-A. The recommended cut-off score of 50 was used to form these groups (La Greca, 1999). A t-test was performed on the state anxiety measure as a validity check to confirm that high social anxiety experienced higher state anxiety in relation to task.

A one-way repeated measures ANOVA was used to investigate the hypothesised interaction between social anxiety level (high/low) and performance rating (self/observer). Hierarchical linear regression was employed to look at the contributions of state anxiety, social performance and a cognitive component of social anxiety (fear of negative evaluation) to the variance in scores on the social anxiety measure. Finally, to investigate the relationship between social anxiety and loneliness Pearson's correlation coefficients were performed.

Results

Participants

Participants (n=20) were 5 females and 15 males, aged between 14 and 21. The mean age of the sample (n= 20) in years was 17.15 (standard deviation= 2.134). Data was gathered from 5 group discussions in 4 different locations. Two groups were held at an independent specialist residential college for people aged 16-25 with ASD (n=9), a further 2 groups were held at 2 specialist secondary education units for people with ASD (n=8) and 1 group was held at a youth club for adolescents with ASD (n=3). Group size ranged from 3 to 5 participants.

Social Anxiety

Results from the anxiety measures are displayed in Table 1.

Table 1: Mean scores and standard deviation on self-report measures of social anxiety, social anxiety factors and state anxiety during the performance task.

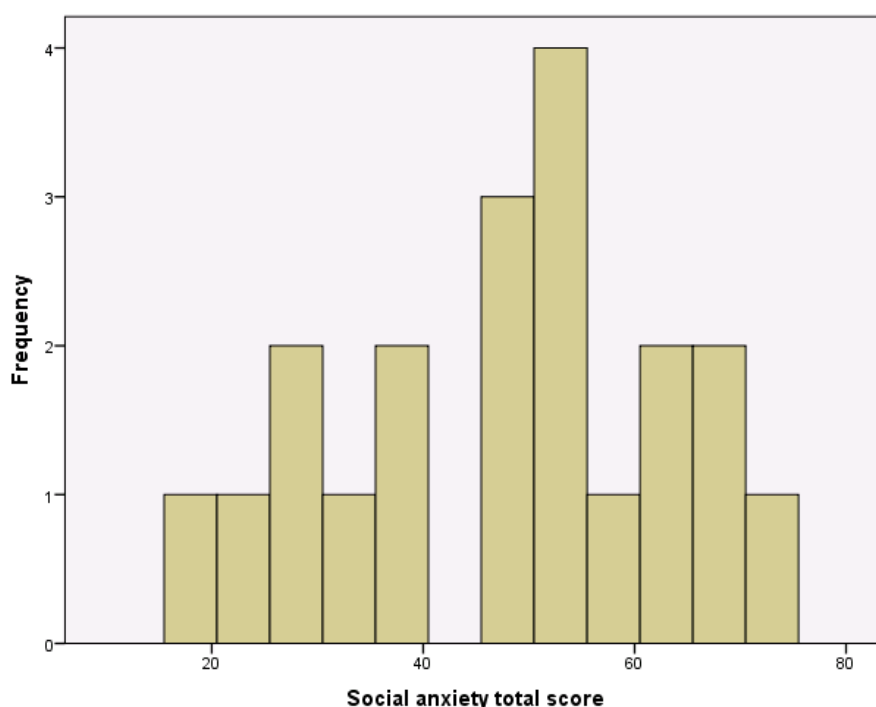
| | N | Mean | SD | Range |
|---------------|----|-------|-------|-------|
| SAS-A Total | 20 | 48.45 | 15.80 | 18-74 |
| FNE | 20 | 20.90 | 8.71 | 8-35 |
| SAD-New | 20 | 17.45 | 5.34 | 6-26 |
| SAD-General | 20 | 10.10 | 4.00 | 4-16 |
| State Anxiety | 20 | 3.60 | 3.14 | 0-10 |

Note: SAS-A Total: Social Anxiety Scale for Adolescents total score; FNE: Fear of negative evaluation; SAD New: distress in new social situations; SAD-General: generalised social distress

Variables were shown to be approximately normally distributed therefore parametric statistics could be employed. The SAS-A demonstrated a Chronbach's Alpha of 0.94 showing excellent internal consistency. Good to excellent internal consistencies were also shown for all the factors (0.94 for FNE, 0.85 for SAD-New and 0.85 for SAD-G). The mean scores of all 3 factors were higher than those of the sample of adolescents reported by La Greca and Lopez (1998). The mean total social anxiety did not differ significantly across the different discussion groups. The mean total social anxiety score was higher for

females (mean female total social anxiety = 59.40, sd= 15.27; mean male total social anxiety= 44.80, sd= 14.66), although this difference was not significant.

Fig 1: Histogram of total social anxiety scores across the sample.



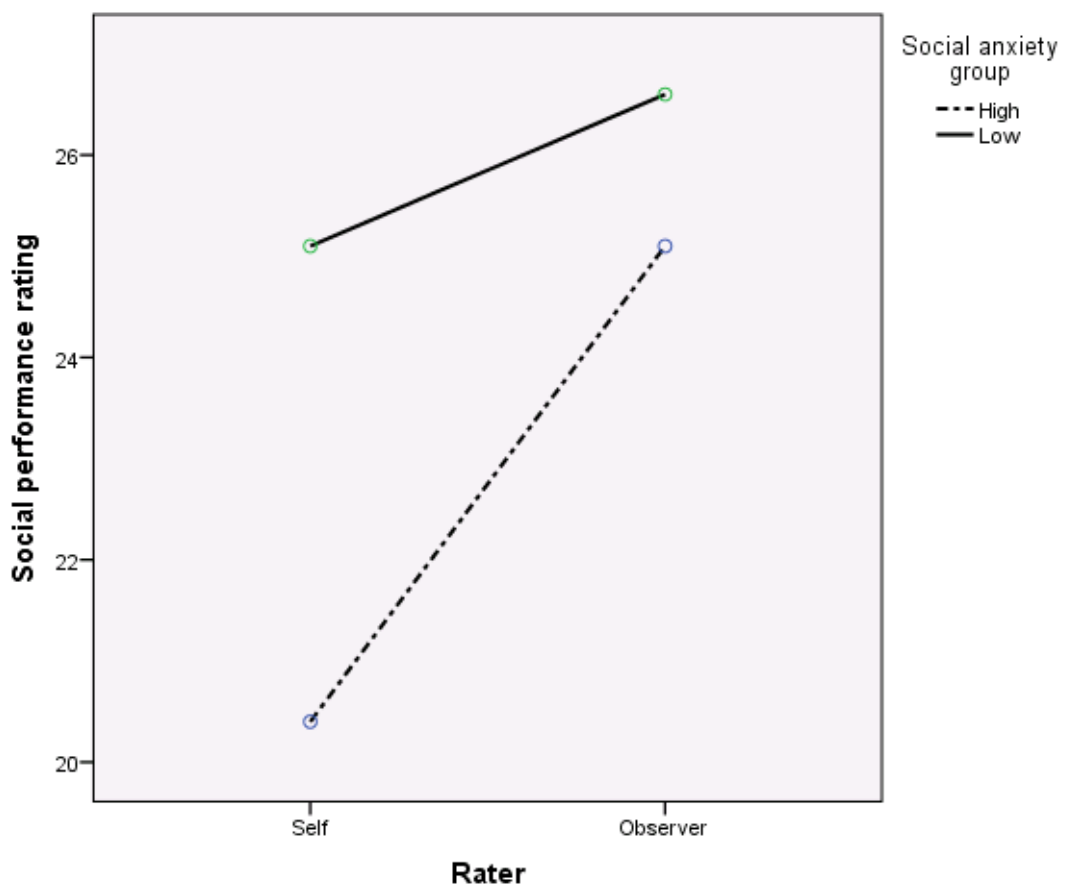
Ten (50%) of the sample scored above the recommended clinical cut off of 50 on the Social Anxiety Scale . The sample was then split using this cut-off score to create two groups; high and low social anxiety. Although there appeared some clustering around the mean, with the modal score being 50-55, the data appeared to be distributed widely enough to make this distinction.

The high and low anxiety groups were compared on their level of state anxiety in the performance task. A one way between groups ANOVA showed that the mean performance state anxiety was higher in the high social anxiety group (mean = 5.30, standard deviation= 3.234) compared to the low social anxiety group (mean= 1.90, standard deviation= 1.969), however this was not a significant between-groups difference ($F(1,18) = 8.065, p = 0.11$).

Social anxiety and performance ratings

A 2 factor mixed ANOVA was used to consider the effects of rater (self and observer) by group (high and low social anxiety). The mean social skills ratings differed significantly by rater ($F(1, 18) = 5.19, p < 0.05$, partial eta squared = 0.22). However, there was not a significant interaction between rater and social anxiety group ($F(1, 18) = 1.38, p = 0.26$, partial eta squared = 0.07). This indicated that self ratings were significantly different to observer ratings but this effect did not significantly differ between social anxiety groups.

Fig 2: Social performance ratings of high and low social anxiety groups according to self and observer rating.



Post-hoc analyses were conducted to look at the mean discrepancies between self and observer ratings of social performance in the high and low social anxiety group. Table 2 shows the mean self and observer ratings and mean discrepancy by group (high and low anxiety) and standard deviations. In the high social anxiety group the t-test showed that self ratings were significantly lower than the

observer ratings ($t(9)=-2.51$, $p<0.05$). In the low anxiety group there was no significant difference between self and observer performance rating.

Table 2: Mean self and observer ratings of social performance in the high and low social anxiety groups.

| Social Anxiety Group | Mean self rating (SD) | Mean observer rating (SD) | Self-Observer Discrepancy Mean, (95% C.I.) |
|----------------------|-----------------------|---------------------------|--|
| High (n=10) | 20.40 (4.14) | 25.10 (5.97) | -4.70* (-8.94-0.46) |
| Low (n=10) | 25.10 (4.677) | 26.6 (5.797) | -1.50 (-5.96-2.96) |

Significance of difference on 1-tailed test * $<.05$, ** $<.01$, *** $<.001$

Due to the inclusion of participants over the age of 18 years, the ANOVA was repeated with age entered as a covariate. The significant main effect of rater disappeared ($F(1,17)= 1.43$, $p=0.25$) and the interaction remained non-significant. To analyse the effect of age further, post hoc analysis looked at the correlation between age and discrepancy in social performance rating (self rating minus observer rating). This correlation was non-significant ($r=0.21$, $p=0.38$).

A stepwise linear regression analysis was conducted to consider the published model of social anxiety (Bellini, 2006) further. Social anxiety total score was entered as the dependent variable, and 3 steps; state anxiety and observer rated social performance entered as step 1 and the measure of the cognitive aspects of social anxiety (Fear of Negative Evaluation) entered as step 2. Age was entered at step 3. The hierarchical multiple regression revealed that at stage one, only state anxiety significantly contributed to the regression model ($F(1,18)= 8.03$, $p<0.05$), accounting for 30.8% of the variance in total social anxiety. When FNE was added to the model, this variable explained an additional 57.1% of the variance in social anxiety scores and revealed a

significant change in R^2 ($F(2, 17)= 61.81, p<0.001$). Age of participants and the observer rating of social skills were not retained in the model.

Social Motivation

One participant did not complete the loneliness questionnaire or satisfaction questions (see Table 3).

Table 3: Mean scores on the loneliness and social satisfaction measures

| | N | Mean | Range | Standard Deviation |
|-----------------------|----|-------|-------|--------------------|
| Loneliness | 19 | 48.53 | 22-73 | 15.01 |
| Satisfaction quantity | 19 | 3.63 | 1-5 | 1.30 |
| Satisfaction Quality | 19 | 4.00 | 2-5 | 0.88 |

The Loneliness questionnaire demonstrated excellent internal consistency with an alpha of 0.93. A significant positive correlation was found between social anxiety and loneliness ($r= 0.482, p< 0.05$). Correlations between FNE and loneliness revealed that these variables were not significantly correlated ($r= 0.333, p= 0.163$). The mean loneliness score was higher for females than males (mean female loneliness= 52.00, sd= 21.74; mean male loneliness= 47.60, sd= 13.56), however this difference was not significant.

The mean ratings on the social satisfaction questions were 3.63 (standard deviation= 1.30, ranging from 1 to 5) for satisfaction with amount of friends and 4.00 (standard deviation= 0.88, ranging from 2 to 5) for satisfaction with quantity of friends. There was no significant difference between the high and low social anxiety groups on either of these satisfaction items. There was a non-significant negative correlation between the satisfaction items and loneliness scores.

Discussion

This study sought to investigate whether negative self-evaluation of social performance is present in adolescents and young adults with ASD high in social

anxiety as has been previously found in typically developing children (Cartwright-Hatton et al., 2003, 2005). Self-ratings of social performance were lower than observer ratings across the sample, however there was no significant interaction between rater and social anxiety group suggesting that the discrepancy between ratings did not differ significantly between groups. Further analysis revealed that participants with ASD who were high in social anxiety showed a significant difference between their self-rating of social performance and observer rating, with their self rating being significantly lower. This difference was not evident in the low social anxiety group. The non-significant interaction may be accounted by the relatively small number of participants, meaning that the study was underpowered.

It was possible to consider the model of social anxiety in ASD (Bellini, 2006) described in the literature in a preliminary fashion. The findings of the present study indicate that a cognitive component (fear of negative evaluation) and state anxiety during the performance task contributed significantly to the variance in scores on the social anxiety measure, with observer ratings of social skills not being retained in the regression equation. Although the regression analysis was limited by sample size, this further supports the notion that social anxiety in this population has a social evaluative aspect, is not just discomfort experienced in social interactions and is potentially independent of objectively rated social skills. Consistent with other studies reported in the literature, social anxiety was a significant problem in this sample of young people with ASD. Half the sample of 14-21 year olds with a diagnosis of ASD scored above the clinical cut-off for social anxiety on a widely used measure (La Greca, 1999) with service level implications. As highlighted by NAS (2010), there is a need to commission mental health services that are able to meet the needs of young people with autism and offer tailored support for this population.

All the factors that comprise the SAS-A (fear of negative evaluation, social avoidance and distress in new situations and social avoidance and distress more generally when in the company of peers) were higher than in the population reported by La Greca and Lopez (1998). This suggests that social anxiety in this population is not merely due to increased physiological arousal, negative

conditioning and limited social skills (Bellini, 2006) but also a fear that the individual will be negatively evaluated. This fear is a core feature of the cognitive model of social anxiety (Clark and Wells, 1995; Clark, 2001), which explains that this perceived social danger follows from certain assumptions about the self e.g. *I'm odd/different* and about the consequences of acting in a certain way e.g. *I'll be rejected*. The appraisal of social danger can then lead to the individual experiencing physiological anxiety symptoms and engaging in safety-seeking behaviours.

As hypothesised, loneliness was significantly correlated with social anxiety, in keeping with previous research (e.g. White and Roberson-Nay, 2009). Fear of negative evaluation, was not significantly correlated with loneliness. Although the relatively small sample size means this must be interpreted with caution, it may be hypothesised that the fear of being negatively evaluated by peers reduces desire for social contact.

This study emphasises the importance of attending to cognitive components of social anxiety in treatment. Although under-powered, results indicate to some degree an association between social anxiety and the under-estimation of social skills. Given that many interventions for young people with ASD focus on teaching social skills, it is necessary to consider the impact of this component in social anxiety-specific interventions. It may be valuable to incorporate components that allow the individual to gain an accurate perception of social skills, such as using video feedback which has been used in CBT interventions for social anxiety disorder. Within social-anxiety-specific interventions it may be less helpful to focus on skill deficit. The relative effectiveness of intervention components and how social anxiety cognitions change over the course of the intervention requires further investigation.

The findings of this study also suggested some gender difference in social anxiety, with females scoring higher than males, although conclusions from this were prevented due to disproportionate groups making the effect non-significant. Despite this, further investigation of such differences are warranted, given the gender effects found in other studies of social anxiety in typically developing

young people (e.g. Inderbitzen-Nolan and Walters, 2000). There is ongoing debate about and research into possible gender differences in the ASD phenotype. In terms of social communication, there are very inconsistent findings, with some studies finding more severe impairments in females (McLennan et al., 1993) and greater social withdrawal (Holtmann et al., 2007) and some finding more comparable levels (Mandy et al., 2012). There appears to be little research into gender differences in anxiety. Females have been reported to be more socially inclined (Gould and Ashton Smith, 2011) which may make them more vulnerable to social anxiety.

Limitations

There are a number of limitations that must be taken into account when interpreting the findings of this study. First and foremost, the low sample size in this study meant that it was underpowered and limits conclusions. Recruiting participants from schools had the advantage of offering established groups of young people, however this also restricted access as some schools were reluctant to be involved. Additionally, the ecological validity must be considered; the participants making up the discussion groups were familiar with each other, attending the same education base or social group and all had ASD. Therefore, anxiety elicited during the performance task is likely to be lower than a task involving unfamiliar participants and participants without ASD, which may better imitate anxiety-provoking social situations in the outside world. In this study, the performance task was a group discussion. In the original studies by Cartwright-Hatton et al. (2003, 2005) the performance task was a presentation and discussion with an unfamiliar adult. These latter tasks may have been more anxiety provoking than the group discussion. A measure of loneliness was used as a proxy for measuring participants' level of social motivation due to loneliness implying in its definition a desire for a greater degree of relationships. However, this may not have accurately reflected the motivation that White et al. (2012) hypothesised to be a primary ingredient in social anxiety. Despite such limitations, this study has revealed some interesting findings that warrant further research.

Conclusion

This study sought to investigate whether young people with ASD who are socially anxious underestimate their social performance as compared to observer ratings. Results indicated that those high in social anxiety did rate themselves more poorly than observers, although the interaction between social anxiety group and rater did not reach significance. To increase the power of this study, a greater number of participants is required. This study presents a case for further investigation of cognitive social evaluative factors associated with social anxiety and ASD such as the fear of negative evaluation and the relative efficacy of focusing on appraisals and cognitions associated, as opposed to social skill tuition, in treatment.

References

- American Psychiatric Association. (2013) Diagnostic and statistical manual (5th ed.). Washington, D.C.: American Psychiatric Association.
- Asher, S. R., Hymel, S., & Renshaw, P. D. (1984). Loneliness in children. *Child Development* 55: 1456–1464. doi: 10.2307/1130015
- Asher, S. R., Parkhurst, J. T., Hymel, S., & Williams, G. A. (1990). Peer rejection and loneliness in childhood. In S. R. Asher, & J. D. Coie (Eds.), *Peer rejection in childhood* (pp. 253-273). New York: Cambridge University Press.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from Asperger Syndrome/high-functioning autism, males and females, scientists and mathematicians (vol 31, pg 5, 2001). *Journal of Autism and Developmental Disorders*, 31(6), 603-603.
- Bauminger, N. & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development* 71: 447-456. doi: 10.1111/1467-8624.00156

- Bauminger, N., Shulman, C., & Agam, G. (2003). Peer interaction and loneliness in high-functioning children with autism. *Journal of Autism and Developmental Disorders* 33: 489–507. doi: 10.1023/A:1025827427901
- Beesdo, K., Knappe, S. & Pine, D.S. (2009) Anxiety and anxiety disorders in children and adolescents: Developmental issues and implications for DSM V. *Psychiatric Clinics of North America* 32(3): 483-524. doi: 10.1016/j.psc.2009.06.002
- Bellini, S. (2004) Social Skill Deficits and Anxiety in High-Functioning Adolescents With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities* 19: 78-86. doi: 10.1177/10883576040190020201
- Bellini, S. (2006a). The development of social anxiety in adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 21: 138–145. doi: 10.1177/10883576060210030201
- C4 Paralympics (2012) *Channel 4 Paralympics - Meet the Superhumans* [online] Available from <http://www.youtube.com/watch?v=tuAPPeRg3Nw>
- Carr, A. (1999) *The Handbook of Child and Adolescent Clinical Psychology: A Contextual Approach* 2nd Ed. Routledge.
- Cartwright- Hatton, S., Hodges, L. & Porter, J. (2003) Social anxiety in childhood: the relationship with self and observer rated social skills. *Journal of Child Psychology and Psychiatry*, 44(5): 737–742. doi: 10.1111/1469-7610.00159
- Cartwright-Hatton, S., Tschernitz, N. & Gomersall, H. (2005) Social anxiety in children: social skills deficit, or cognitive distortion? *Behaviour Research and Therapy* 43: 131–141. doi: 10.1016/j.brat.2003.12.003

- Clark, D. (2001) A Cognitive Perspective on Social Phobia. In W. Ray Crozier & Lynn E. Alden (eds) *International Handbook of Social Anxiety: Concepts, Research and Interventions Relating to the Self and Shyness*. (pp. 405-430) John Wiley & Sons Ltd.
- Clark, D. M. & Wells, A. (1995). A cognitive model of social phobia. In R. Heimberg, M. Liebowitz, D.A. Hope, & F. R. Schneier (Eds.), *Social phobia: Diagnosis, assessment and treatment*. (pp. 69–93). New York: Guilford Press Sussex: Wiley.
- Farrugia, S., & Hudson, J. (2006). Anxiety in adolescents with Asperger syndrome: Negative thoughts, behavioral problems, and life interference. *Focus on Autism and Other Developmental Disabilities* 21: 25–35. doi: 10.1177/10883576060210010401
- Gould, J. & Ashton-Smith, J. (2011) Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice* 12(1): 34-41.
- Hodson, K.J., McManus, F.V., Clark, D.M. & Doll, H. (2008) Can Clark and Wells' (1995) Cognitive Model of Social Phobia be Applied to Young People? *Behavioural and Cognitive Psychotherapy* 36(4): 449-461. doi: 10.1017/S1352465808004487
- Holtmann, M., Bolte, S., & Poustka, F. (2007). Autism spectrum disorders: sex differences in autistic behaviour domains and coexisting psychopathology. *Developmental Medicine and Child Neurology*, 49(5), 361-366.
- Inderbitzen-Nolan, H. M., & Walters, K. S. (2000). Social Anxiety Scale for Adolescents: Normative data and further evidence of construct validity. *Journal of Clinical Child Psychology*, 29(3), 360-371. doi: 10.1207/s15374424jccp2903_7
- Kuusikko, S., Pollock-Wurman, K.J., Jussila, K., Carter, A.S., Mattila, M., Ebeling, H. Pauls, D.L. & Moilanen, I. (2008) Social anxiety in high-functioning

children and adolescents with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders* 38(9): 1697-1709. doi: 10.1007/s10803-008-0555-9

La Greca, A.M. (1999) *Manual for the Social Anxiety Scales for Children and Adolescents*. University of Miami; Miami

La Greca, A. M., & Lopez, N. (1998). Social anxiety among adolescents: Linkages with peer relations and friendships. *Journal of Abnormal Child Psychology*, 26(2), 83-94. doi: 10.1023/a:1022684520514

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304-1313. doi: 10.1007/s10803-011-1356-0

McLennan, J. D., Lord, C., & Schopler, E. (1993). SEX-DIFFERENCES IN HIGHER FUNCTIONING PEOPLE WITH AUTISM. *Journal of Autism and Developmental Disorders*, 23(2), 217-227. doi: 10.1007/bf01046216

Muller, E., Schuler, A. & Yates, G.B. (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism* 12: 173-180. doi: 10.1177/1362361307086664

The National Autistic Society (2010) *You Need to Know*. The National Autistic Society. Available from <http://www.autism.org.uk/get-involved/campaign-for-change/learn-more/our-campaigns/past-campaigns/you-need-to-know/resources.aspx>

Roberson-Nay, R., Strong, D. R., Nay, W. T., Beidel, D. C., & Turner, S. M. (2007). Development of an abbreviated Social Phobia and Anxiety Inventory (SPAI) using item response theory: The SPAI-23. *Psychological*

Assessment, 19(1), 133-145. doi: 10.1037/1040-3590.19.1.133

Schohl, K. A., Van Hecke, A. V., Carson, A. M., Dolan, B., Karst, J., & Stevens, S. (2014). A Replication and Extension of the PEERS Intervention: Examining Effects on Social Skills and Social Anxiety in Adolescents with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 44(3), 532-545. doi: 10.1007/s10803-013-1900-1

Sofronoff, K., Attwood, T., & Hinton, S. (2005). A randomised controlled trial of a CBT intervention for anxiety in children with Asperger syndrome. *Journal of Child Psychology and Psychiatry*, 46(11), 1152-1160. doi: 10.1111/j.1469-7610.2005.00411.x

White, S.W. & Roberson-Nay, R. (2009) Anxiety, Social Deficits, and Loneliness in Youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders* 39: 1006-1013. doi: 10.1007/s10803-009-0713-8

White, S.W., Albano, A.M., Johnson, C.R., Kasari, C., Ollendick, T., Klin, A., Oswald, D. & Scahill, L. (2010) Development of a Cognitive-Behavioral Intervention Program to Treat Anxiety and Social Deficits in Teens with High-Functioning Autism. *Clinical Child and Family Psychology Review* 13: 77-90. doi: 10.1007/s10567-009-0062-3

White, S.W., Bray, B.C. & Ollendick, T.H. (2012) Examining Shared and Unique Aspects of Social Anxiety Disorder and Autism Spectrum Disorder Using Factor Analysis. *Journal of Autism and Developmental Disorders* 42: 847-884. doi: 10.1007/s10803-011-1325-7

White, S.W., Oswald, D., Ollendick, T. & Scahill, L. (2009) Anxiety in children and adolescents with Autism Spectrum Disorders. *Clinical Psychology Review* 29(3):216-229. doi: 10.1016/j.cpr.2009.01.003

Wood, J. J., Drahota, A., Sze, K., Har, K., Chiu, A., & Langer, D. A. (2009).

Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: a randomized, controlled trial. *Journal of Child Psychology and Psychiatry*, 50(3), 224-234. doi: 10.1111/j.1469-7610.2008.01948.x

Vernberg, E. M., Abwender, D. A., Ewell, K. K., & Beery, S. H. (1992). SOCIAL ANXIETY AND PEER RELATIONSHIPS IN EARLY ADOLESCENCE - A PROSPECTIVE ANALYSIS. *Journal of Clinical Child Psychology*, 21(2), 189-196. doi: 10.1207/s15374424jccp2102_11

Executive Summary of Main Research Project

Young people with autism spectrum disorders (ASDs) are more likely to experience anxiety and mood disorders than the typically developing population. Social anxiety disorder, which is the persistent fear of being around other people, is one such disorder which is particularly prevalent.

The cognitive behavioural model is the most supported model for understanding and treating social anxiety disorder. This model identifies that cognitions play a central role in maintaining the anxiety. These cognitions or thoughts and beliefs often involve negative ideas about the self and the ability to perform in social situations. It has been demonstrated that typically developing children who are high in social anxiety rate their social performance more negatively than an observer. This study aimed to see if this occurs for young people with ASD who are high in social anxiety. A second aim was to look at the association between social anxiety and loneliness, as it had previously been shown that social anxiety is linked to loneliness and the desire for more social contact.

Twenty people with ASD aged 14-21 years-old and who were in full time education took part in the study. The participants completed measures of social anxiety, loneliness and social satisfaction. Following this they took part in a group discussion made up of between 3 and 5 participants, the researcher and in some cases a research assistant. The discussion lasted approximately 10 to 15 minutes and was based on a short piece of film. After the discussion each

participants rated the level of anxiety they experienced during the task and filled in a questionnaire rating aspects of their social skills. The researchers later watched the recording of the discussion and rated the social performance of the participants on the same aspects.

Half the sample scored above the recommended clinical cut off point for social anxiety, meaning that 50% had clinically significant social anxiety. Based on the social anxiety scores, the sample of participants were divided into two groups for the analysis: high and low social anxiety. Analysis of their social performance ratings showed that the high anxiety group rated themselves significantly lower than observers. This difference was not shown in the low social anxiety group. There was minimal difference in the observer ratings of the high versus low social anxiety group. However, the discrepancy between the self and observer ratings did not differ significantly between the high and low social anxiety groups. Loneliness significantly correlated with social anxiety in this sample.

This study was limited by the relatively small number of participants who took part. However the study supports previous studies that have shown social anxiety to be a significant problem in this in adolescents and young adults with ASD. Results highlight the cognitive aspects of social anxiety; the fear of being negatively evaluated by other people and the negative perceptions of one's social performance. More investigation is needed into such aspects of social anxiety. There is a need to consider the relative effectiveness of cognitive components in interventions.

Connecting Narrative

Part of the appeal of Clinical Psychology training for me was the emphasis on research being integrated into clinical practice. The Doctorate in Clinical Psychology course has given me the opportunity to further my research skills using a wide variety of approaches, including completing single case designs, and service related pieces of research. This narrative will outline my main research project, service improvement project, critical review of the literature and case studies to describe my research experience through Clinical Psychology training.

Main Research Project

Study selection and development

My main research project investigated the impact of social anxiety on how young people with Autism Spectrum Disorder (ASD) rate their social performance. The research was based on previous research which found that typically developing young people high in social anxiety rate their performance more poorly than those low in anxiety, despite no difference in observer rating. The study also explored the impact of cognitive factors on social anxiety and the relationship with loneliness.

I selected this topic due to my interest in anxiety disorders in young people and my recent clinical experience using Clark's model of social anxiety. Discussions with my clinical tutor, Dr. Ailsa Russell, sparked an interest in anxiety disorders in young people with ASD which appeared to be a complex area, lacking in research. I then engaged a highly experienced field supervisor, Eddy Draper, who was supportive and helped to further develop my ideas and create important contacts in the region.

Ethical approval

As I was not recruiting participants from NHS sources, I was not required to obtain National Research Ethics Service (NRES) clearing. I gained ethical approval from the University Ethics committee. This procedure necessitated me to know my procedure in depth and produce all relevant paper work and helped me to be clear and concise in my writing. I was not in complete agreement with certain issues raised by the committee. However, the process encouraged me to consider the research from a number of standpoints and be flexible to adapt to the requirements of the committee. There appeared to be a lack of clear pathway in gaining ethical approval to work with educational establishments, which left me unsettled at times. I gained ethical approval from Somerset County Council which covers the education units I would target. This was supported by Peter Harnett, Lead Educational Psychologist for ASD services in Somerset, who was a great asset in helping me access participants.

Recruitment

It was decided with my supervisors that I would recruit participants from schools, education bases and social groups as it was not necessary for my sample to be a clinical population. Furthermore, these recruitment sources would offer established groups of people from whom I could create a discussion group. I felt it was important to build relationships with the establishments by visiting initially to meet staff and again to meet students and invite them to take part.

Discussions with educational staff brought up issues that I had not considered in depth. For example, one teacher was concerned about the young people's ability to self report anxiety, which I then considered in my method of measurement. Generally, the time invested in building relationships with education bases and social group paid off as staff members were very supportive of the research. The interest expressed by many staff members was reassuring to me regarding the clinical utility of the piece of work.

However, I quickly realised how small and widespread the education bases were, therefore recruiting participants was time consuming. Further attempts at recruiting participants through schools were not as successful; six schools or colleges that I initially made positive contact with decided they did not wish to be

involved due to already being involved in research or reluctance to take on further tasks.

Data collection

An undergraduate placement student, Sangeet Fletcher, accompanied and assisted my data collection at two education bases. I carried out the other data collection independently. I enjoyed meeting the young people who participated in my research and received a range of reactions. Many young people were keen to be involved, others appeared more cautious and some questioned my hypotheses and methodology. I had not anticipated this latter response and realised the importance of having a detailed debrief prepared, which I had not given much planning.

Challenges and personal learning

Aside from the recruitment difficulties, a key challenge was conducting the statistical analysis, ensuring I had a good knowledge of the tests and could make accurate interpretations of the output. I ensured I invested enough time to thoroughly understand relevant tests. Throughout this piece of research I learnt about my personal style of working, how I tend to work efficiently and independently, however I recognised that continual discussion and advice-seeking from my supervisors is essential to ensure a high quality piece of research.

Contributions to clinical practice

It was important for me to continually relate my research back to clinical practice and ensure its clinical utility. The main contribution of this piece of research is the attention that is drawn to the cognitive aspects of social anxiety for young people with ASD, an aspect that is lacking in existing models in the literature. The study's main hypothesis was not supported significantly, however I predict with a higher number of participants this may change. I plan to continue with recruitment to increase the power of the study.

Service Improvement Project

Study selection and development

My interest in young people was also reflected in my choice of Service Improvement Project. This was a qualitative study looking at the experiences of young people and their parents in the transition from paediatric to adult cystic fibrosis (CF) services, to help inform developments in how this transition is managed.

This opportunity arose from my contact with the psychologists in the Bristol Children's Hospital to investigate current research interests. I was put in touch with my field supervisor, Dr. Samantha Phillips, who was interested in evaluating transition experiences. This project appealed to me due to the previous experience as an Assistant Psychologist relating to transition for young people with complex needs and knowing that transition is a very current issue in healthcare. This project was given the go ahead by the course team and I was allocated Dr. Kate Rimes to be my internal supervisor.

Samantha Phillips and I met on a number of occasions to develop the research questions and to explain the current practices around transition. Samantha also directed me to relevant literature. I was aware of the current interest in the field of transition and of the expanse of research and policies already in existence. The volume of literature was helpful to some degree but also difficult to synthesise. It also led me to question how, despite this vast amount of available literature, clinicians remain concerned with the management of transition. To help further gain a more local perspective on transition I met with the head of Psychological Services at Bristol Children's Hospital, Sue Dolby who update me on developments in other areas such as diabetes. I also met with the young people's involvement coordinator at the Children's Hospital to gain advice about practically conducting the study.

The transition steering group, comprising of clinicians from both the paediatric and adult teams, began to meet quarterly. Attending these meeting helped refine the topic guide and also alerted me to the range of opinions within the team

regarding transition, the responsibilities of the staff in this area and the boundaries of this.

On reflection, further use of my internal supervisor would have offered a perspective that was detached and objective.

Ethical approval

Ethical approval was granted from the University of Bath Psychology Research Ethics Committee. Similarly to my main research project, full NRES was not a requirement for this project as, following discussion with supervisors and the Research and Development department, it was decided that it constituted service evaluation and was given approval for this. However, I realised how this is a grey area. Due to the project being a service evaluation I had to ensure that questions continually related back to the service despite my interest in personal meanings and experiences.

Process

The qualitative research methodology of this project appealed to me due to my previous experience and I was keen to build on skills in this area but put a greater emphasis on service recommendations. I noticed how current qualitative literature in the area lacked specific service recommendations.

Engaging with service users to understand their experiences of transition allowed me to gain some understanding of life for a young person with chronic illness and their parent. I was surprised by the amount of emotional and practical challenges facing both the patients and parents during the time of transition. I previously underestimated the significance of transition for young people and families. I was touched by one young person's positivity about the improvements in health outcome for young people with CF, despite the limited life expectancy.

It was important to stay very self-reflective when interpreting themes, acknowledging my own background and training and how this may have affected how the participants answered questions and how I interpreted their responses. Having a very supportive internal supervisor separate from the CF team helped me to recognise my personal influence and also the influence of the rest of the

multidisciplinary team. Due to staff changes, Dr. Joanna Adams supervised the analysis of the project. I transcribed the interviews and annotated transcripts, identifying initial emerging themes. My supervisor then did the same, blind to my own interpretations. Meeting and discussing emerging themes was crucial to aid reliability and think through the structure of themes.

My field supervisor, Samantha Phillips, offered feedback on my analysis and helped me broaden my perspective. We reflected and hypothesised about the possible influences on the families' narratives, for example, negative reports about the adult team may be influenced by the anxiety about change and the loss of a long relationship with the children's service.

There have been multiple opportunities to feed back my work and this has greatly increased my confidence in public speaking and the facilitation of discussion. The findings were fed back to the steering group meeting, the paediatric CF team meeting and are due to be presented at the CF regional day and the European Cystic Fibrosis Conference.

Feeding back to the families involved was also important to ensure they felt heard. I wrote a letter to all participants thanking them for their involvement and also summarising the findings and plans for service developments.

Challenges and personal learning

One of the key areas of learning and development for me whilst completing this project has been translating qualitative research findings into service-level change. This project has also allowed me to develop my skills in facilitating group discussion, acknowledging and drawing together a variety of views. I have valued the opportunity to be part of a multi-disciplinary team. This has included experiencing some resistance at times from some healthcare professionals. It was paramount to build positive relationships with the team and consider how staff may perceive the findings and recommendations.

On a practical note, one of the main challenges was recruitment; there was a relatively low rate of participation, which was at times disheartening. However, this highlighted the challenges in conducting research in such settings.

Contributions to clinical practice

Despite there being much literature in the area of transition, this project contributes to this field by bringing it to a more local level. The study highlighted the significance of the change, the range of emotions experienced, and the issues that appear to have most impact such as relationship change. Despite the service having in place some transition practices which mainly focused on healthcare independence, there are clear areas where improvements can be made, e.g. supporting patients and parents to build new relationships. This was a small sample so such recommendations are made with caution and are being developed through discussions with staff to ensure viability.

Critical Review of the Literature

Study selection

My Service Improvement Project highlighted the effects of transition on parents as well as the patients themselves and the importance of recognising the experiences of the whole family. My critical review of the literature focused on the experiences of family members who have a relative with obsessive compulsive disorder (OCD).

I selected this area to build on my interest in anxiety disorders in young people but I wanted to think more critically about existing interventions and understand more about the involvement of the family. When looking into the literature base on OCD and the family it appeared to be dominated by the concept of family accommodation, with many cross-sectional correlational studies. Teaching on the course has really emphasised the meaning that people attribute to their experiences and how this is at the core of many psychological disorders. I therefore considered the meanings that families place on OCD and how this may influence their own coping and psychological wellbeing.

Dr. Claire Lomax supervised this piece of work and helped me to focus the review to look at the concepts of coping and burden. We decided that reviewing

literature across the lifespan would be valuable to draw on commonalities and differences. To help narrow the review and make it feasible, we decided to not include literature that focused primarily on family accommodation as this had been recently reviewed elsewhere..

Focusing the review was difficult and highlighted the importance of identifying specific inclusion and exclusion criteria. Even with a relatively small number of articles, synthesising the studies to consider them together was challenging. I learnt the importance of developing a process of data extraction and synthesis and would like to read more around this methodology to aid future reviews. I developed a way of visually representing my results and finding commonalities and discovered that I benefit from such visual methods.

Personal learning

By conducting this review I developed a better understanding of theoretical models of coping and burden and also specific knowledge within the area of OCD. I became more confident in being critical of research and this is something that I envisage will continue to develop with experience.

Contributions to the literature base

This review has drawn attention to the far-reaching effects of OCD on family members and the wide-spread burdens that may be experienced. Some studies have developed models of how coping strategies are related to outcome, e.g. how reduced hope is associated with avoidance which in turn is associated with depression. Such research has certain clinical value however more longitudinal, clinical data is needed in this area. It appears that there is a paucity of research that looks at the meanings and appraisals of OCD by family members, which would help tie together findings using existing theoretical models.

Case studies

Completing case studies on each placement has made me aware of the challenges of embedding research into clinical practice but also of the benefits. The production of case reports for each placement has helped me take a more evidence based, critical approach to the work that I have undertaken, which I

believe has increased the quality of my clinical work. My first placement in an IAPT service allowed me to practice and embed CBT skills and use psychological measures each session to better monitor change over time. I established the use of psychological measures from the start of the treatment intervention, ensuring that they were discussed in session and used to inform the direction of intervention. This has benefitted me subsequently as I have learnt that data collection can be embedded within clinical practice. In subsequent placements, however, conducting experimental case studies has been challenged by cultures that do not place value on the use of psychological measures.

My case studies reflect the range of clinical work completed. In different reports I have focused on different aspects of the role of Clinical Psychology. For example, I have focused on assessment in two of the case reports; one neuropsychological and one attachment-based. In one report I emphasise systemic formulation with other professionals. In the remaining two reports I focus on CBT intervention. I have developed my ability to use and develop theory-practice links by routing each case in existing evidence base and considering how each contributes to understanding within the area.

Continuing research post-qualification

The continued integration of research into clinical practice post qualification is of great importance to me. I recognise how the research experiences of training have helped me establish the skills needed to be a scientist-practitioner and I also acknowledge how I would like to continue to develop these further. I foresee challenges in doing this, for example, practical issues such as the resources and protected time to keep a breadth of research and to carry out research studies. Discussions with supervisors have highlighted the need to protect time for research purposes in job contracts and the importance of highlighting the value for services in carrying out research. I would expect that service related research that focuses on improvement would be more supported and viable. I would like to further develop my knowledge of the integration of research into qualified practice by, for example, developing skills in developing research bids. I also

hope to maintain links with the University of Bath and support projects of future trainee Clinical Psychologists.

Research Appendices

Appendix A: *Clinical Child and Family Psychology Review* Instructions for Authors

Types of papers
Original Paper, Review Paper

Submission
Submissions are by editor invitation only.

Peer Review

All manuscripts undergo peer review
Manuscript submission
Invited authors will receive instructions from the editor about how to submit their manuscript online. Electronic submission substantially really reduces the editorial processing and reviewing times and shortens overall publication time.

Title Page

The title page should include:
The name(s) of the author(s)
A concise and informative title
The affiliation(s) and address(es) of the author(s)
The e-mail address, telephone and fax numbers of the corresponding author

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Text

Text Formatting
Manuscripts should be submitted in Word.
Use a normal, plain font (e.g., 10-point Times Roman) for text.
Use italics for emphasis.
Use the automatic page numbering function to number the pages.
Do not use field functions.
Use tab stops or other commands for indents, not the space bar.
Use the table function, not spreadsheets, to make tables.
Use the equation editor or MathType for equations.
Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX.
LaTeX macro package (zip, 182 kB)

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols. Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.

Terminology

Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

Please use the standard mathematical notation for formulae, symbols etc.:

Italic for single letters that denote mathematical constants, variables, and unknown quantities

Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative)

Bold for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal article

Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001).

Writing labs and the Hollywood connection. *Journal of Film Writing*, 44(3), 213–245.

Article by DOI

Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. *Journal of Molecular Medicine*, doi:10.1007/s001090000086

Book

Calfee, R. C., & Valencia, R. R. (1991). *APA guide to preparing manuscripts for journal publication*. Washington, DC: American Psychological Association.

Book chapter

O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), *Gender issues across the life cycle* (pp. 107–123). New York: Springer.

Online document

Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association.
http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

Journal names and book titles should be italicized.

For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

EndNote style (zip, 3 kB)

TABLES

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

ARTWORK AND ILLUSTRATIONS GUIDELINES

Electronic Figure Submission

Supply all figures electronically.

Indicate what graphics program was used to create the artwork.

For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.

Vector graphics containing fonts must have the fonts embedded in the files.

Name your figure files with "Fig" and the figure number, e.g., Fig1.eps

Appendix B: *Health Psychology* Instructions for Authors

Prior to submission, please carefully read and follow the submission guidelines detailed below. Manuscripts that do not conform to the submission guidelines may be returned without review.

Submission

The main emphasis of *Health Psychology* is on original research in health psychology. Analytical reviews of research and brief scientific reports are also considered for publication. Submissions are welcomed from authors in psychology and other health-related disciplines.

[Submit manuscripts electronically](#) (.rtf, PDF, or .doc) to

Anne E. Kazak

Center for Healthcare Delivery Science

A.I. du Pont Hospital for Children

Administration and Research Building, Room 281

1600 Rockland Road

Wilmington, DE 19803



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In recognition of the reality that institutional spam filters may capture files from the APA and the Journals Back Office, please take the following steps to facilitate communication with our editorial office:

Provide an alternative email address which we can use to contact you in the event of technical difficulties with email communication using your primary address;

Add "apa.org" to your list of "safe" addresses and consider asking your IT administrators to add it to their "white list;" and

Information About Submissions

The page limit for research manuscripts is 25–30 pages. The page limit is inclusive of **all** parts of the manuscript, including the cover page, abstract, text, references, tables and figures.

Authors may request consideration of longer papers, in advance of submission, when there is clear justification for additional length (e.g., the paper reports on two or more studies or has an unusual or complex methodology).

Scholarly reviews and meta-analyses should not exceed 25 pages, but tables and references may be outside this page limit.

Brief reports are encouraged for innovative work that may be premature for publication as a full research report because of small sample size, novel methodologies, etc. Brief reports should be designated as such and should not exceed a total of 12 pages, inclusive of **all** parts of the manuscript, including the cover page, abstract, text, references, tables and figures.

All manuscripts should be double-spaced, with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller).

Authors should submit a suggestion of three potential reviewers for their article.

Health Psychology considers letters concerning previously published articles. Letters should be no more than 500 words and have a maximum of five references.

Authors also have the option of placing supplemental materials online.

Submissions that exceed the page limits will be returned to the author for shortening prior to the initiation of peer review.

Submission Letter

The cover letter should indicate that the authors have read and followed the *Health Psychology* Instructions for Authors. It should also include a statement indicating that the paper has been seen and approved by all authors. The cover letter should describe how the paper advances research in health psychology, referring to the journal mission to assure that the submission fits with the types of papers published in *Health Psychology*.

The full mailing address, telephone, fax, and email address for the corresponding author should be included in the cover letter and title page, along with the names and affiliations of all co-authors.

The cover letter must confirm that the manuscript has not been published, is not currently submitted elsewhere, and that it does not contain data that is currently submitted or published elsewhere.

When a manuscript contains data that is part of a larger study, authors should describe the larger study and provide references for other study papers. Authors must be prepared to provide copies of related manuscripts when requested as part of the editorial review process. Authors should clarify the relationship between their paper, including detailed specification of the overlap in participants, measures, and analysis, and others from the study. The value-added scientific contribution of their study must be clearly stated in the cover letter.

Authors of brief reports should indicate in the cover letter that the full report is not under consideration for publication elsewhere and similarly address potential overlap with other papers.

Manuscripts

The manuscript title should be accurate, fully explanatory, and no longer than 12 words. The title should reflect the content and population studied. If the paper reports a randomized clinical trial, this should be indicated in the title. The title of brief reports should start with the words "Brief Report".

The title page should include the names of all authors and their affiliations at the time the research was done. This information will be masked to ensure a blind peer review process by the editorial office. Authors should make sure that all other identifying information in the text of the paper is masked/removed prior to submission.

All manuscripts must include a structured abstract containing a maximum of 250 words with the following sections:

Objective (brief statement of the purpose of the study);

Methods (summary of the participants, design, measures, procedure);

Results (primary findings); and

Conclusions (specific statement of the implications of the data).

Please supply up to five keywords or brief phrases after the abstract. The Introduction should not exceed 3–4 pages in length. The paper should be referenced appropriately but excessive citations should be avoided.

All research involving human participants must describe oversight of the research process by the relevant Institutional Review Boards and should describe consent and assent procedures briefly in the Methods section.

All statistical tests should include effect size whenever possible.

First person language ("I", "we") should be avoided. Terminology should be sensitive to the individual who has a disease or disability. The journal endorses the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of people with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

It is important to highlight the significance and novel contribution of the work. The translation of research into practice must be evidenced in all manuscripts. Authors should incorporate a meaningful discussion of the clinical and/or policy implications of their work throughout the manuscript, rather than simply providing a separate section for this material.

Health Psychology publishes a broad array of types of papers. Authors of qualitative and measure development papers should read the guidelines for these types of papers, noted below.

Qualitative Research

Research papers that utilize qualitative methods should follow the general instructions to authors for style and format. We ask that authors of qualitative papers review the additional guidance below to assure that papers meet the following criteria utilized by *Health Psychology*.

The introduction should make a compelling case for the significance of the study and clearly identify if the study is a stand-alone study or if it fits into a larger study. For example, qualitative manuscripts may inform the development of a survey, use small-incident samples, or establish feasibility. The specific qualitative paradigm should be specified (e.g., grounded theory, qualitative descriptive approach, interpretive phenomenology) with a rationale as to why it was selected to address the research question.

At the same time, authors are encouraged to avoid methodological tutorials and cite appropriate references for the methodology. Describe your sampling frame clearly and how the sample was selected, justifying the type and size of your sample using appropriate language for qualitative studies.

While many qualitative studies may not use a conceptual model, if you have done so, explain how the model may have shaped the design, data collection, analysis and interpretation. Explain carefully how you strengthened and insured rigor in your study e.g., data analysis protocols (including how coders were trained), audit procedures, and demonstration of data saturation. Describe the data analysis and how it relates to your overall approach or paradigm. Present rich and compelling results with data that have been analyzed and interpreted appropriately for your method (e.g., discourse analytic results would be presented differently than those of a grounded theory).

The paper should convey how this research fills an important gap in the science and promises to change the way we approach future studies.

Masked Review Policy

Masked review is used. **Do not** include author information (addresses, phone numbers, electronic mail addresses, and fax numbers) in the manuscript.

Please ensure that the final version for production includes a byline and full author note for typesetting.

Use of CONSORT Reporting Standards

All randomized controlled trials must include a diagram indicating participant flow into the study and a completed CONSORT checklist. CONSORT diagrams (and adaptations) should be included whenever possible to clarify the flow of participants through a study.

Manuscript Preparation

Prepare manuscripts according to the [Publication Manual of the American Psychological Association \(6th edition\)](#). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's [Checklist for Manuscript Submission](#) before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

We request that runnable source code be included as supplemental material to the article. For more information, visit [Supplementing Your Article With Online Material](#).

In the Text of the Article

If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font

with a type size of 8 points. We will make an image of each segment of code in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.) If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Submitting Supplemental Materials

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see [Supplementing Your Article With Online Material](#) for more details.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

Journal Article:

Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin*, 139, 133–151.
<http://dx.doi.org/10.1037/a0028566>

Authored Book:

Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

Chapter in an Edited Book:

Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, [please see the general guidelines](#).

When possible, please place symbol legends below the figure instead of to the side.

APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:

\$900 for one figure

An additional \$600 for the second figure

An additional \$450 for each subsequent figure

Permissions

Authors of accepted papers must obtain and provide to the editor on final acceptance all necessary permissions to reproduce in print and electronic form any copyrighted work, including test materials (or portions thereof), photographs, and other graphic images (including those used as stimuli in experiments).

On advice of counsel, APA may decline to publish any image whose copyright status is unknown.

Publication Policies

APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications.

See also [APA Journals® Internet Posting Guidelines](#).

APA requires authors to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test or procedure, funding by pharmaceutical companies for drug research).

[Download Disclosure of Interests Form \(PDF, 38KB\)](#)

Authors of accepted manuscripts are required to transfer the copyright to APA.

For manuscripts **not** funded by the Wellcome Trust or the Research Councils UK

[Publication Rights \(Copyright Transfer\) Form \(PDF, 83KB\)](#)

For manuscripts funded by the Wellcome Trust or the Research Councils UK

[Wellcome Trust or Research Councils UK Publication Rights Form \(PDF, 34KB\)](#)

Ethical Principles

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.

Authors are required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment.

Appendix C: University Hospitals Bristol Trust approval emails for Service Improvement Project

From: Watkin, Tony

Sent: 19 December 2012 11:24

To: Gane, Catherine

Cc: Lewis, Paul

Subject: FW: Service evaluation - CF Transition project

Approved as below.

Tony ☺

Tony Watkin

Public Involvement Project Lead

University Hospitals Bristol NHS Foundation Trust

Quality Team

Trust Headquarters

Marlborough Street

Bristol
BS1 3NU

Telephone: 0117 342 3729

www.uhbristol.nhs.uk
tony.watkin@uhbristol.nhs.uk

From: Swonnell, Chris
Sent: 19 December 2012 11:16
To: Watkin, Tony
Cc: Lewis, Paul
Subject: RE: Service evaluation - CF Transition project

Tony – I agree that they appear to have given plenty of thought.
Approved
Chris

From: Watkin, Tony
Sent: 19 December 2012 11:10
To: Swonnell, Chris
Subject: RE: Service evaluation - CF Transition project

Chris

This is for fast tracking please with subsequent noting in the QS files.

These are semi structured interviews with young CF patients. Paul and Cath have worked with Helen Wood at Taunton NHS FT to develop the interviews. I have reviewed the paperwork today and, other than making sure the covering letter is appropriately formatted, support approval. They have gone to a great deal of care in my view.

You have here the template, a note about the process and a composite file containing consent, letter and interview themes.

Tony

Tony Watkin
Public Involvement Project Lead

University Hospitals Bristol NHS Foundation Trust
Quality Team
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Telephone: 0117 342 3729

www.uhbristol.nhs.uk
tony.watkin@uhbristol.nhs.uk

Appendix D: Ethics approval from University of Bath Psychology research Ethics Committee for Service Improvement project

Helen Lucey [hl259@bath.ac.uk]

Sent: 22 January 2013 11:01

To: M
Wood Helen (TAUNTON AND SOMERSET NHS FOUNDATION TRUST)

Cc: M
Caroline Ransford [C.A.Ransford@bath.ac.uk]

Dear Helen

Thank you for attending to those questions and for sending the approval email from QIS.

I can now confirm that you have full ethical approval for your study.

Best wishes with your research.

Helen Lucey

Appendix E: *Journal of Autism and Developmental Disorders* Instructions for Authors

Editorial procedure

Double-Blind Peer Review

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information. The blinded manuscript containing no author information (no name, no affiliation, and so forth). The Author Note

Types of papers

Articles, Brief Reports, Letters to the Editor, Commentaries

The preferred article length is 20-23 manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.

A Brief Report or Case Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.

A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures. Style sheet for Letter to Editor & Case Reports:

Style sheet for Letter to the Editor AND Case Report:

A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information

The blinded manuscript containing no author information (no name, no affiliation, and so forth):-

- 6 or less double spaced pages with shorter references, tables and figures

- Line 1: "Letter to the Editor"

- Line 3: begin title (note: for "Case Reports start with "Case Report: Title")

- Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

Review your manuscript for these elements

1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Blinded Manuscript without contact information and blinded Abstract, and References

Appendix

Figure Caption Sheet

Figures

Tables

Author Note

MANUSCRIPT SUBMISSION

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Authors should submit their manuscripts online. Electronic submission substantially reduces the editorial processing and reviewing times and shortens overall publication times. Please follow the hyperlink "Submit online" on the right and upload all of your manuscript files following the instructions given on the screen.

Title page

The title page should include:

The name(s) of the author(s)

A concise and informative title

The affiliation(s) and address(es) of the author(s)

The e-mail address, telephone and fax numbers of the corresponding author

Abstract

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Text

Text Formatting

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 10-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.

Body

The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:

Introduction (The introduction has no label.)

Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)

Results (Center the heading.)

Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

Center the label "Footnotes" at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Author Note

The first paragraph contains a separate phrase for each author's name and the affiliations of the authors at the time of the study (include region and country).

The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".)

The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study.

The fourth paragraph states, "Correspondence concerning this article should be addressed to..." and includes the full address, telephone number and email address of the corresponding author.

Terminology

Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

Please use the standard mathematical notation for formulae, symbols etc.:

Italic for single letters that denote mathematical constants, variables, and unknown quantities

Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative)

Bold for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal article

Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. *Journal of Film Writing*, 44(3), 213–245.

Article by DOI

Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. *Journal of Molecular Medicine*, doi:10.1007/s001090000086

Book

Calfee, R. C., & Valencia, R. R. (1991). *APA guide to preparing manuscripts for journal publication*. Washington, DC: American Psychological Association.

Book chapter

O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), *Gender issues across the life cycle* (pp. 107–123). New York: Springer.

Online document

Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association. http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

Journal names and book titles should be italicized.

For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

[EndNote style \(zip, 3 kB\)](#)

TABLES

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

ARTWORK AND ILLUSTRATIONS GUIDELINES

For the best quality final product, it is highly recommended that you submit all of your artwork – photographs, line drawings, etc. – in an electronic format. Your art will then be produced to the highest standards with the greatest accuracy to detail. The published work will directly reflect the quality of the artwork provided.

Electronic Figure Submission

Supply all figures electronically.

Indicate what graphics program was used to create the artwork.

For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.

Vector graphics containing fonts must have the fonts embedded in the files.

Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Figure Lettering

To add lettering, it is best to use Helvetica or Arial (sans serif fonts).

Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).

Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.

Avoid effects such as shading, outline letters, etc.

Do not include titles or captions within your illustrations.

Figure Numbering

All figures are to be numbered using Arabic numerals.

Figures should always be cited in text in consecutive numerical order.

Figure parts should be denoted by lowercase letters (a, b, c, etc.).

If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,

"A1, A2, A3, etc." Figures in online appendices (Electronic Supplementary Material) should, however, be numbered separately.

Figure Captions

Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.

Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.

No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.

Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.

Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

When preparing your figures, size figures to fit in the column width.

For most journals the figures should be 39 mm, 84 mm, 129 mm, or 174 mm wide and not higher than 234 mm.

For books and book-sized journals, the figures should be 80 mm or 122 mm wide and not higher than 198 mm.

Permissions

If you include figures that have already been published elsewhere, you must obtain permission from the copyright owner(s) for both the print and online format. Please be aware that some publishers do not grant electronic rights for free and that Springer will not be able to refund any costs that may have occurred to receive these permissions. In such cases, material from other sources should be used.

Accessibility

In order to give people of all abilities and disabilities access to the content of your figures, please make sure that

All figures have descriptive captions (blind users could then use a text-to-speech software or a text-to-Braille hardware)

Patterns are used instead of or in addition to colors for conveying information (colorblind users would then be able to distinguish the visual elements)

Any figure lettering has a contrast ratio of at least 4.5:1

Figure caption sheet

The figure caption sheet contains a list of only the captions for all figures used. Center the label "Figure Captions" in uppercase and lowercase letters at the top of the page. Begin each caption entry flush left, and type the word "Figure", followed by the appropriate number and a period, all in italics. In the text of the caption (not italicized), capitalize only the first word and any proper nouns. If the caption is more than one line, double-space between the lines, and type the second and subsequent lines flush left. Table notes: Copyright permission footnotes for figures are typed as part of the figure caption.

Each figure should appear on a separate page. The page where the figure is found should have the figure number and the word "top"[ie, Figure 1 top] typed above the figure. Figures or illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Figures may be embedded in the text of a Word or Wordperfect document. Electronic artwork submitted on disk may be in the TIFF, EPS or Powerpoint format (best is 1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. Assistance will be provided by the system administrator if you do not have electronic files for figures; originals of artwork may be sent to the system administrator to be uploaded. *** After first mention in the body of the manuscript, a call-out for the correct placement of each figure should be included in brackets on a separate line within the text.

ELECTRONIC SUPPLEMENTARY MATERIAL

Springer accepts electronic multimedia files (animations, movies, audio, etc.) and other supplementary files to be published online along with an article or a book chapter. This feature can add dimension to the author's article, as certain information cannot be printed or is more convenient in electronic form.

Submission

Supply all supplementary material in standard file formats.

Please include in each file the following information: article title, journal name, author names; affiliation and e-mail address of the corresponding author.

To accommodate user downloads, please keep in mind that larger-sized files may require very long download times and that some users may experience other problems during downloading.

Audio, Video, and Animations

Always use MPEG-1 (.mpg) format.

Text and Presentations

Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.

A collection of figures may also be combined in a PDF file.

Spreadsheets

Spreadsheets should be converted to PDF if no interaction with the data is intended.

If the readers should be encouraged to make their own calculations, spreadsheets should be submitted as .xls files (MS Excel).

Specialized Formats

Specialized format such as .pdb (chemical), .wrl (VRML), .nb (Mathematica notebook), and .tex can also be supplied.

Collecting Multiple Files

It is possible to collect multiple files in a .zip or .gz file.

Numbering

If supplying any supplementary material, the text must make specific mention of the material as a citation, similar to that of figures and tables.

Refer to the supplementary files as "Online Resource", e.g., "... as shown in the animation (Online Resource 3)", "... additional data are given in Online Resource 4".

Name the files consecutively, e.g. "ESM_3.mpg", "ESM_4.pdf".

Captions

For each supplementary material, please supply a concise caption describing the content of the file.

Processing of supplementary files

Electronic supplementary material will be published as received from the author without any conversion, editing, or reformatting.

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The manuscript contains a descriptive caption for each supplementary material

Video files do not contain anything that flashes more than three times per second (so that users prone to seizures caused by such effects are not put at risk)

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Manuscripts submitted for publication must contain a statement to the effect that all human and animal studies have been approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

It should also be stated clearly in the text that all persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the subjects under study should be omitted.

These statements should be added in a separate section before the reference list. If these statements are not applicable, authors should state: The manuscript does not contain clinical studies or patient data.

The editors reserve the right to reject manuscripts that do not comply with the above-mentioned requirements. The author will be held responsible for false statements or failure to fulfill the above-mentioned requirements

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If no conflict exists, authors should state: The authors declare that they have no conflict of interest.

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The article will be published online after receipt of the corrected proofs. This is the official first publication citable with the DOI. After release of the printed version, the paper can also be cited by issue and page numbers.

Appendix F: University of Bath Psychology Research Ethics approval for Main Research Project

Psychology-Ethics [psychology-ethics@bath.ac.uk]

Sent: 13 September 2013 14:49

To: M
Wood Helen (TAUNTON AND SOMERSET NHS FOUNDATION TRUST)

Cc: M
Caroline Ransford [C.A.Ransford@bath.ac.uk]; psychology-ethics@bath.ac.uk

Dear Helen,

Ethics Reference Number 13-133

Thank you for satisfactorily attending to those amendments.

I can now

confirm that you have full ethical approval for your study.
Best wishes with your research.

Appendix G: Somerset County Council approval for Main Research Project

'Social Anxiety and Self Perceptions in Young People with ASD'

Project Information

We are inviting you to take part in a research project. Please read the information below and decide if you want to take part. The research is being run by Helen Wood who is a Clinical Psychologist in training from The University of Bath.

Background information

Lots of young people find social situations difficult. Young people who have a diagnosis of an autism spectrum condition may find these even more difficult.

We would like to find out how you feel in social situations.

What will happen?

First, you will fill in some questionnaires asking about social situations.

You will not put your name on the form so no one will know who put what.



Then you will invited to watch a short film about popular culture.

Following this there will be a 10-15 minute group discussion with up to 5 other young people and the researcher about the film.

After the discussion we will ask you to fill in another questionnaire about how you think it went.



We will film the discussion. The only people who will watch the film will be the researcher, the research assistant and the research supervisor who works at the University of Bath. They will also fill in a questionnaire about how it went.

When the researchers have watched the film it will be destroyed.



It is your choice whether you take part. There are no problems with not taking part. If you decide to take part and then change your mind that is fine. You can withdraw at any time.

What we find out from the study will be put into a report. Your name or any other information that might identify you will not go in this report.

As a thank you for your time, each participant will receive a voucher. If you have any questions please email Helen: H.wood2@bath.ac.uk

Thank you

Helen Wood
Clinical Psychologist in Training
University of Bath

Appendix I: Main Project information sheet for parents



Parent information

Your son/daughter has been invited to take part in a research project looking at social anxiety and concerns among young people on the autism spectrum. Please read this information carefully to help decide if you are happy for their involvement.

Social concerns and anxiety are commonly reported in young people, especially those with social and communication difficulties. We want to find out more about this so that we know how best to help with such concerns.

What will taking part in the research mean?

We will ask the young people who take part to fill in a questionnaire which asks about social anxiety and feelings of loneliness. The young people will then watch a short piece of film about an aspect of popular culture.

There will then be a discussion group to share opinions about the topic of the film.

The group will be made up of the researcher (Helen Wood) and up to 5 participants. This discussion will be filmed. Following the discussion, the participants will rate how they think they performed in the group in terms of social skills. The film will later be looked at and coded by the researchers. If your son/daughter would like to take part in the project and you give consent for this, they have the right to withdraw their participation at any time. This will not have any negative effects on their schooling.

If your son/daughter becomes upset at any time, Helen Wood, who is a Clinical Psychologist in training, will offer appropriate support and the staff may be informed.

Confidentiality

Confidentiality will be maintained – the name of the young people will be removed from all questionnaires before they are given to the researcher. No names or identifiable details will be written in the report.

How will footage be stored?

The footage of the discussion groups will be kept securely on a password protected computer. This will be permanently deleted when the results have been gathered.

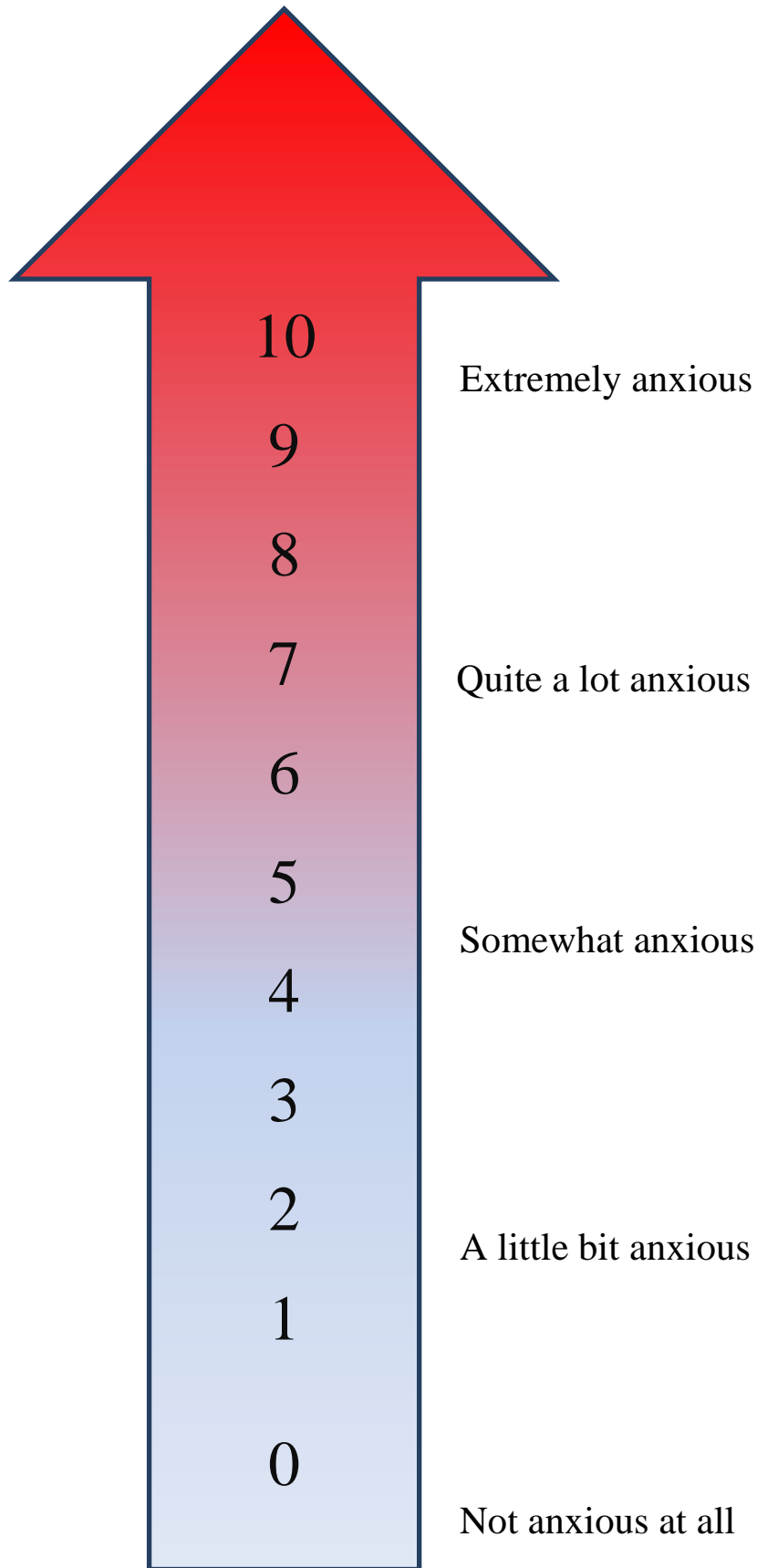
What will happen with the findings?

The findings will be written into a report which will form part of Helen Wood's Doctorate in Clinical Psychology research. This report will also be submitted for publication in a journal so may be available to a large amount of people. The write up will be confidential and your son/daughter will not be identifiable.

Appendix J: State Anxiety Scale

How anxious did you feel during the discussion?

Please circle the number that best matches how anxious you felt.



Appendix K: Social performance self rating

Please think about how the group discussion went then circle how much you agree with the following statements...

| | | | | |
|--|----------------|-------|----------|-------------------|
| I spoke confidently | Strongly agree | Agree | Disagree | Strongly disagree |
| I seemed friendly | Strongly agree | Agree | Disagree | Strongly disagree |
| I spoke clearly | Strongly agree | Agree | Disagree | Strongly disagree |
| I seemed clever | Strongly agree | Agree | Disagree | Strongly disagree |
| I was good at making eye contact | Strongly agree | Agree | Disagree | Strongly disagree |
| What I said in the group was really good | Strongly agree | Agree | Disagree | Strongly disagree |
| I appeared nervous | Strongly agree | Agree | Disagree | Strongly disagree |
| I smiled | Strongly agree | Agree | Disagree | Strongly disagree |
| I blushed | Strongly agree | Agree | Disagree | Strongly disagree |